

Turning strain into strength: Exploring the positive psychological changes and growth-ful
developments in the loved ones providing care for persons with Parkinson's Disease

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Abstract

Parkinson's disease (PD) is a degenerative disease that progressively impacts physical, psychological and social functioning resulting in diminished quality of life (D'Antonio, Zimmerman, & Iacono, 2000; Den Oudsten, Van Heck, & De Vries, 2007; Montel, Bonnet, & Bungener, 2009). The negative effects of PD are not only experienced by persons with PD but also their loved ones – such as their spouses and to a lesser extent their adult-children – because they become the primary caregivers as the disease progresses (D'Amelio et al., 2009). PD caregiving literature has focused predominantly on the negative effects of caregiving, namely caregiver burden (see Aarsland et al., 2007; Caap-Ahlgren & Dehlin, 2002; Harbishettar et al., 2010). The positive effects of PD caregiving remain a less-explored phenomenon. Existing literature suggests that PD caregiving is primarily a negative, burdensome and stressful experience without sufficient acknowledgement of the possible lived experience of PD caregiving and caregivers' strengths. This interpretative-phenomenological study was designed with a strengths-based perspective (Saleebey, 2012) to explore the lived experience of loved ones providing care for persons with PD. Participants were the primary caregivers for a family member with PD, either spouses or adult-children, residing in the same home as the person with PD. Data collection phase one involved in-depth semi-structured interviews ($N = 29$). Data collection phase two involved a small focus group ($N = 3$), as a supplementary measure to draw upon insights and clarify emergent themes from phase one. The transcripts were analysed using an integration of interpretative phenomenological analysis (IPA; Smith & Eatough, 2012) and thematic analysis (TA; Braun & Clarke, 2006). The analysis identified five master themes (and 20 sub-themes): (1) Positive changes in perspectives on living, (2) Personal Growth, (3) Relationship growth, (4) Contextual experience associated with positive changes and growth-ful development, and (5) Lacking in positive changes and growth-ful development. Results indicated a substantial

number of loved ones providing care reported positive psychological changes and growthful development associated with PD caregiving. However, many others could not identify any positive experiences, only loss and strain since the presence of PD in their lives.

Analysis revealed that participants employed meaning-making processes such as deliberate rumination (i.e., life re-evaluation and re-prioritisation), searching for significance (i.e., benefit finding and positive reappraisal), and cognitive processes (i.e., assimilation and accommodation), as well as emotional processing (i.e., exploring and expressing emotions) in a supportive environment (i.e., PD support groups). This resulted in outcomes of meaning made, such as perceptions of positive psychological changes and growthful development (i.e., positive changes in attitude, and ways of thinking and being). Findings are consistent with influential growth theories, such as the *adversity-activated development theory* (AAD) (Papadopoulos, 2007), the *revised meaning-making model* (Park, 2010) and the *post-traumatic growth theory* (Calhoun, Cann, & Tedeschi, 2010; Tedeschi & Calhoun, 2004)). Each postulate that people can grow and develop both personally and relationally as a result of a stressful experience (Park, 2010), exposure to ongoing adversity (Papadopoulos, 2007), and post-trauma or major life crisis (Calhoun, Cann, & Tedeschi, 2010; Tedeschi & Calhoun, 2004).

Conclusions were consistent with previous caregiving research from other populations (e.g., Farran et al., 1999; Rapp & Chao, 2000; Sanders, 2005) where the PD caregiving situation is associated with loss and compromise, much like dementia caregiving. However, the potential for positive experiences and growthful developments is apparent. The precise circumstances where caregiving activities generated everyday strain (e.g., tension, losses, burden, and stress) for the loved ones providing care also appeared to create moments of appreciation and gratification, and allowed for positive transformation and growthful development.

This study contributes to the caregiving literature by balancing out the pre-existing negative attentional bias of conventional PD caregiving research by demonstrating the positive side of caregiving. Moreover, this study revealed novel findings pertaining to personal growth that have previously been underexplored. For example, in this study, the loved one providing care reported becoming better at respecting the person with PD's boundaries, and existential needs for autonomy and independence, as a result of the unique challenges of the PD caregiving situation. Furthermore, this study extends previous research by providing an understanding of the underlying cognitive and psychological processes that may be necessary for positive psychological change and growth-ful development in PD caregiving.

Findings have clinical and practical implications for clinicians when designing psychological interventions for the loved ones providing care for persons with PD. As such, interventions should be designed to create an environment conducive to growth-ful development, to facilitate and enhance meaning-making processing skills (e.g., deliberate rumination, life reflection and re-evaluation, mindful acceptance coping, psychological flexibility, and positive reappraisal), as well as encouraging support group attendance and creating opportunities in the PD community for loved ones to share their growth narratives in order to enhance the likelihood of positive outcomes amongst a community of those affected by PD.

Keywords: Parkinson's disease (PD), person with PD (singular), persons with PD (plural), loved ones providing care, positive psychological changes, growth-ful development.

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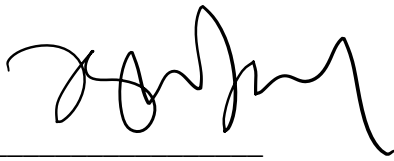
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Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other education institution. To the best of my knowledge and belief, the thesis contains no material previously published by another person except where due to reference is made.

Signature:

A handwritten signature in black ink, consisting of a series of loops and a long horizontal stroke at the end, positioned above a horizontal line.

Date:

___31/10/2016___

Statement of Contributions

This thesis was made possible through the contributions of others

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Meta-view Summary of Thesis

The purpose of this section is to present an outline of the thesis and provide an overview of this research project as well as providing definitions of the terms used throughout the thesis. This thesis is arranged in eight chapters. This first introductory chapter provides a background and context to this research project. Whilst this study focuses on the caregiving experience of the loved ones providing care for persons with PD, as opposed to the experience of persons with PD, the introductory chapter contains a brief background to PD, the PD caregiver role and context, and existing PD caregiving research.

The PD caregiving literature has shown that loved ones providing care for persons with PD experience many negative effects as a result of this caregiving, including caregiver burden (e.g., Aarsland et al., 2007; Caap-Ahlgren & Dehlin, 2002; Harbishettar et al., 2010), depression (Carter, Stewart, Lyons, & Archbold, 2008; Goldsworthy & Knowles, 2008; Martinez-Martin et al., 2008), health problems (K. S. Kim et al., 2007; Lau & Au, 2011; McKinlay et al., 2008), personal and relationship loss (Cifu et al., 2006; McRae et al., 2009), and diminished quality of life (Kelly et al., 2012; Morley et al., 2012; O'Connor & McCabe, 2011). Despite these negative effects, there is evidence that there are positive experiences associated with caregiving, such as deriving a sense of satisfaction from performing caregiving tasks while providing care for a loved one (Farran, Loukissa, Perraud, & Paun, 2003, 2004; Tarlow et al., 2004). These positive experiences have been found to buffer against common detrimental consequences of PD caregiving (Carter, Lyons, Stewart, Archbold, & Scobee, 2010; Goldsworthy & Knowles, 2008; Konstam et al., 2003). Moreover, it has been found that these positive effects not only allow caregivers to be resilient to the demands of caregiving, but also provide unique opportunities for growth such as personal and relationship growth (Netto, Goh Yen Ni, & Yap Lin Kiat, 2009; Peacock et al., 2010; Sanders, 2005).

However, when examining the PD caregiving literature, there appears to be a lack of published research that has focused on self-perceived positive psychological changes and growthful development associated with PD caregiving. Research on this topic has primarily focused on dementia caregivers (Netto et al., 2009; Peacock et al., 2010; Sanders, 2005); the loved ones of cancer survivors (Manne et al., 2004; Mosher, Danoff-Burg, & Brunker, 2006; Weiss, 2004); the loved ones of stroke survivors (Bacon, Milne, Sheikh, & Freeston, 2009; Coombs, 2007; Hallam & Morris, 2013); and bereaved caregivers who provided care for a loved one with a terminal illness such as HIV (Cadell, 2003, 2007; Carlisle, 2000) or cancer (Seltzer & Li, 2000; Wong, Ussher, & Perz, 2009). Given that positive caregiver psychological change and growthful development has been reported in other caregiving populations, it is possible that PD caregiving may also provide an opportunity for positive psychological change and growthful development for loved ones providing care for persons with PD. Hence, in the absence of such research, there is a need to explore this topic in more depth.

Chapter One briefly highlights the gaps in existing PD caregiving research and provides an extensive rationale for this research. Chapter One concludes by outlining the study aims and question; to investigate the positive psychological changes and growthful development associated with PD caregiving.

Positive experiences, such as caregiver satisfaction, suggest contentment or having expectations met without necessarily implying that the caregiver has grown from the caregiving experience (Netto et al., 2009). Whereas the concept of growth suggests a gain that supersedes previous levels of adaptation, expectations, psychological functioning or life awareness (Tedeschi & Calhoun, 2004). *Growth through caregiving* refers to “any positive affective or practical return that is experienced as a direct result of becoming a caregiver” (Kramer, 1997 p. 219). For example, *personal growth through caregiving* involves “feelings

of continued development, perceiving the self as growing and expanding, seeing improvement in the self and in behaviour over time, and emanating both an openness to new experiences and flexibility to change in ways that reflect enhanced self-knowledge and effectiveness resulting specifically from the caregiving situation rather than from life experience in general” (Leipold, Schacke, & Zank, 2008, p. 204). In other words, a caregiver may have grown personally, beyond pre-existing levels of adaption, as a result of providing care for a loved one with a chronic illness. The concept of growth through caregiving by Leipold et al. (2008) is adopted in the present study.

Rather than adopting Kramer’s concept of *growth through caregiving*, this study adopts the subtly different term *growth-ful development* (Papadopoulos, 2007). Papadopoulos (2007) argues that growth when related to living beings often means an increase in size or having more importance. Growth is termed as a physical change, whereas development means transformation and improvement. Development refers to the process of developing skills and capabilities, and not only deals with the physical change but also behavioural, social and psychological changes. Papadopoulos claims that the term growth-ful development allows for a wider variation in positive response than growth. While growth is related to quantitative improvement, development is related to quantitative as well as qualitative improvement. Hence the term growth-ful development is better suited to the present study as it is concerned with investigating development (e.g., skills and abilities) associated with PD caregiving. Moreover, it is acknowledged in this study that all research that measures growth-ful development, in either qualitative or quantitative research, relies on participants’ self-report. In other words, regardless of whether an individual (in the present study’s case, the loved one providing care) completes a scale, or responds to an interview question, the response garnered is *self-perceived growth-ful development(s)*. Hence, this more apt term is used in the present study.

There are many growth-theories that could explain positive psychological change and growth-ful development as a result of PD caregiving. However, none of these have been used to investigate or explain this phenomenon in PD caregiving. Within the second chapter the theories of growth that inform the present study will be explained. These theories are: (1) the revised meaning-making model (Park, 2010), (2) the adversity-activated development theory (Papadopoulos, 2007), and (3) the post-traumatic growth theory (Calhoun, Cann, & Tedeschi, 2010; Tedeschi & Calhoun, 2004). This chapter presents an argument as to why proponents from each theory are adopted within the context of investigating the positive experiences of PD caregiving. This chapter also presents the theoretical conceptualisations of the present study, informed by each of the three growth theoretical models.

Chapter One briefly highlights the gap in the existing PD caregiving research, while Chapter Three emphasises the gap in more detail. Hence, Chapter Three details a literature review, including the less-researched positive experiences and growth-ful development derived from PD caregiving. This chapter also reviews literature from other caregiving populations that have more extensively focused on positive experiences and growth-ful developments (i.e., dementia caregiving and loved ones of cancer survivors). This chapter presents a critique of methodology used in previous caregiving studies, and in doing so presents a narrative of the researcher's choice in adopting a suitable methodology for the current study.

The fourth chapter presents the research framework for the study and specifically outlines and describes IPA (Smith and Eatough, 2012). IPA was chosen because it is a suitable approach to address the study question and aims to capture the lived experience of loved ones providing care for persons with PD. IPA is compatible with the theoretical assumptions brought to the study, and the subjective, transformative and existential nature of the research focus, question and aims.

The fifth chapter describes the methods used to complete the study. Ethical considerations, participant recruitment, data collection methods, data analysis and management, as well as the strategies used to enhance rigour are discussed. Typically, there are two possible ways of presenting the results and discussion in IPA studies (Smith & Osborn, 2008). One such way is to present the results (which contain the emergent thematic analysis) and the discussion together in a single chapter, discussing the links between themes and the extant literature. The second way is to present results and discussion separately in standalone chapters. The current study adopts the latter strategy.

The sixth chapter outlines the findings of the study and presents them in themes and sub-themes derived from the analysis. This chapter demonstrates the way participants make sense of their lived experience, whilst the researcher makes sense of the participants making sense of their lived experience. This chapter takes the form of a narrative interplay between the researched (loved ones providing care) and the researcher interposed with verbatim extracts from participants' accounts (interview transcripts).

The Discussion chapter presents the interpretations and explanations of the findings (themes and sub-themes) utilising growth theories and models in the context of existing literature. The aim here is to gain an in-depth and rich analysis and to do more justice to the totality of the person providing care, as well as the positive PD caregiving experience.

Chapter Eight presents the clinical and practical implications of the findings and outlines recommendations for clinical practice, and possible psychological interventions to better support the loved ones providing care for persons with PD. In this chapter, the study's strengths and limitations are outlined and discussed, and recommendations for further research will be made to address these limitations. This thesis concludes with the contributions of this research.

Chapter One: Introduction

The purpose of this chapter is to orientate the reader to the research and provide context to following chapters. As stated the thesis summary, a brief background to PD will be provided because knowledge about PD, and the possible challenges and concerns imposed by the disease is essential to understand the context of the PD caregiver role. The background of PD includes prevalence, symptomology, and will describe the nature of this disease. The PD caregiver role and context will then be described before providing a brief overview of the negative effects and then positive effects of PD caregiving. The rationale for this study along with the study's research purpose, aims, and question will also be presented, which will conclude this chapter.

1.1 Background of Parkinson's Disease

1.1.1 Prevalence. Globally, PD is the second most common neurological disorder after dementia (Razali, Ahmad, Abd Rahman, Midin, & Sidi, 2011). In 2014, it was conservatively estimated that over 69,200 Australians were living with PD, of which it was estimated 53% were male and 47% female (Deloitte Access Economics, 2015). On average, 32 new cases are diagnosed every day and 11,900 new cases will be diagnosed in 2015 (Parkinson's Australia, 2014). Typically, people who are diagnosed are aged 60 years and older, with 20% being diagnosed between 40 and 60 years of age, and 10% at age 40 years and under (Deloitte Access Economics, 2015). There has been an estimated 27% increase in the number of PD cases since 2005. This increase is largely attributed to the aging population, and is estimated to increase further as the average age of the population continues to rise (Deloitte Access Economics, 2015). In Australia it is estimated that by 2031 there will be approximately 115,300 persons with PD, equating to an average growth in prevalence of 4% per annum over the next 20 years (Deloitte Access Economics, 2011).

1.1.2 Motor and non-motor symptoms. PD was originally conceptualised as a movement disorder because those affected typically experience difficulties with voluntary movement and motor control resulting from degeneration of the substantia nigra (Parkinson, 2002). The substantia nigra is responsible for producing the neurotransmitter dopamine (Arden & Linford, 2009). Since dopamine plays a major role in controlling movement (Antonelli & Strafella, 2014), dopamine deficiency has been implicated in the classical motor symptoms that characterise PD (Factor & Weiner, 2008). These motor symptoms are slowness in movement and speech, tremor, and stiffness or rigidity (Jankovic, 2008; Koller & Marjama-Lyons, 2001). Hence, PD has traditionally been known in lay terms as the “shaking disease” because tremor was the most apparent and well-known feature or symptom of the disease (Jankovic, 2008).

However, over the past half-decade there has been growing recognition for the non-motor symptoms that often accompany PD (Chaudhuri, Healy, & Schapira, 2006; Forjaz, Chandiramani, & Martinez-Martin, 2011; Weintraub & Burn, 2011; Zesiewicz, Sullivan, & Hauser, 2006), as well as increasing acknowledgement that PD is much more than just the shakes (Shake It Up Foundation, 2014). Non-motor symptoms can include depression, anxiety, apathy, pain, hallucinations, autonomic dysfunction (e.g., loss of smell, constipation, hypotension, and excessive sweating), cognitive impairment, and for some in advanced stages of PD, dementia (Forjaz et al., 2011; McKinlay et al., 2008; Todorova & Chaudhuri, 2013). Most recently PD has been posited as “quintessentially a neuropsychiatric disorder” (Weintraub & Burn, 2011) because of the extensive non-motor symptoms that can accompany the disease. Table 1 shows the broad spectrum of both motor and non-motor symptoms that can accompany a PD diagnosis.

Table 1

Motor and Non-motor symptoms that can accompany PD

<i>Motor Symptoms</i>	<i>Non-motor Symptoms</i>	
Tremor	Psychological symptoms or disorders	Autonomic Symptoms
Slow movement and reaction times	Depression, Apathy, Anhedonia,	Bladder disturbances
Loss of spontaneous movement and gestures,	Anxiety, Panic attacks	Sweating
Loss of facial expression,	Obsessional and repetitive behaviour	Hypotension
Decreased blinking/staring appearance, and	Hallucinations and Psychosis*	Sexual dysfunction
freezing)	Cognitive symptoms	Hypersexuality*
Rigidity and stiffness of limbs and trunk	Cognitive impairment	Erectile impotence should it be erectile dysfunction?
Postural instability	Slow thought processing (bradyphrenia)	Dry eyes
Impaired balance and coordination	Tip-of-the-tongue phenomenon (difficulty finding	Gastrointestinal symptoms
Reduced arm swing while walking	words)	Nausea
Shuffling	Attention deficit problems	Constipation
Impaired Speech (e.g., talking in a soft voice)	Confusion	Faecal incontinence
Motor speech disorder	Delirium*	Sensory symptoms
Impaired swallowing	Dementia	Pain, secondary to rigidity
Drooling as a result of impaired swallowing	Sleep Disorders	Tingling of skin
Excessive salivation	Insomnia	Olfactory disturbance (e.g., loss of smell)
Small hand writing	Restless legs syndrome	Other Symptoms
Involuntary tapping of forehead	Rapid eye movement sleep disorder	Fatigue
Involuntary closing of the eyelids	Vivid dreaming	Oily skin
Involuntary spasms or contractions	Sleep disordered breathing	
Striatal deformity, Scoliosis		

Note. * = may be induced by medication. PD = Parkinson's disease. Adapted from "Non-motor symptoms of Parkinson's disease: diagnosis and management" by K. R.

Chaudhuri, D. G. Healy, and A. H. V. Schapira, 2006, *The Lancet Neurology*, p. 235 and "Parkinson's disease: clinical features and diagnosis," by J. Jankovic, 2008, *Journal of Neurology, Neurosurgery & Psychiatry*, p.3

1.1.3 Nature of the disease. PD is a unique disease because the wide spectrum of motor and non-motor symptoms manifest uniquely in each individual (Braak et al., 2006). In other words, Parkinson's affects every sufferer differently, and as such, the disease trajectory and extent of disability varies for each individual. The unique nature of the disease makes it difficult to generalise across persons with PD and contributes to difficulties with the diagnosis, prognosis, treatment, and management of the disease (McLaughlin et al., 2011). Consequently, the unique nature of the disease poses many challenges for persons with PD, their loved ones, and for health professionals.

Typically, the disease progresses slowly over approximately a 20-year period (Jankovic, 2008), but for some the disease progresses more rapidly. The rate of progression depends on the unique manifestations of the disease in each individual (Jankovic & Kapadia, 2001). Therefore, both persons with PD and loved ones are faced with an uncertain future with regards to progression, making it difficult to learn how to cope with a condition that has such a variable prognosis (Dyck, 2009). Wressle, Engstrand, and Granérus (2007) found that loved ones of persons with PD struggle more with the uncertain and ambiguous nature of the disease, and worried more about their future and the negative impacts of the disease, than did the persons with PD. This emphasises the negative effects of the disease not just on the persons with PD but also the loved ones.

During the early stages of the disease the symptoms are subtle and the disease poses minimal limitations and restrictions. During this stage, persons with PD often remain independent and do not require much, if any, assistance with activities for daily living. However, the persons with PD become progressively slower and more uncoordinated as the disease progresses (Jankovic, 2008). It becomes increasingly difficult to perform household tasks and personal responsibilities such as personal hygiene, dressing, and eating (Wressle, et al., 2007). Essentially, any task requiring fine motor skills becomes increasingly difficult

(e.g., buttoning, tying shoes, using utensils, getting out of a chair or bed), especially for those affected with the tremor. As a result of the physical limitations and restrictions imposed by the disease, persons with PD become progressively dependent on those around them for assistance with activities for daily living. Often the primary fear for persons with PD is becoming a burden on family members and consequently losing their independence (Chiong-Rivero et al., 2011). Inevitably, the disease determines a progressive loss of autonomy (D'Amelio et al., 2009; Frazier, 2000), taking from persons with PD, not only their freedom of movement, but also their freedom of speech and thought. The latter stages of the disease are thus marked by significant disability. During the most advanced stage of the disease, persons with PD may be restricted to a wheelchair or even bedridden, unable to speak or feed themselves, rendering them entirely dependent on others (Koller & Marjama-Lyons, 2001).

Despite recent and rapid advancements in PD research, PD remains incurable (Goetz, 2013). PD continues to be one of the least understood neurological diseases in terms of its cause and the aetiology of PD remains essentially unknown (Deloitte Access Economics, 2011). Notwithstanding, it is widely acknowledged that a genetic predisposition as well as environmental factors may trigger this disease (Bartels & Leenders, 2009). A genetic predisposition is considered a risk factor, and it is estimated that 15% to 20% of persons with PD have a first-degree relative who has also experienced PD symptoms (Deloitte Access Economics, 2011). Other proposed causes are accelerated ageing, oxidative damage, and environmental toxins (Deloitte Access Economics, 2011). Most recently, PD has been described as having a complex multi-factorial aetiology (Goetz, 2013).

Parkinson's Disease is not considered a life-threatening disease, rather, like dementia, PD is considered a life-limiting disease. It is estimated that the median time from PD onset to death is 12.4 years and the average age of onset is 76 years (Deloitte Access Economics, 2015). Therefore, persons with PD typically remain in the early to mid-stage of the disease

for approximately 10 years, and usually do not progress to the advanced stages, but die instead of other co-morbidities. The most common cause of death is pneumonia, due to dysphagia (problems swallowing) and disordered respiratory mechanisms that occur in the latter stages of the disease (Hely, Morris, Reid, & Trafficante, 2005; Williams-Gray et al., 2013).

1.2 PD Caregiver: Role and Context

Family members, typically the spouse and less often adult children, either by choice or necessity, assume the PD caregiving role (Australian Bureau of Statistics, 2012a). They do so, often without any formal training in caregiving (Razali et al., 2011), and frequently feel unprepared for this role (Davey, Wiles, Ashburn, & Murphy, 2004). Family members usually engage in caregiving for numerous reasons. The most common reason is a sense of responsibility followed by a strong desire to do so because they perceive they can provide better care than anyone else, or because there is no one else available or willing to provide the necessary care (Australian Bureau of Statistics, 2012b).

Family caregivers are classified in the literature as “informal primary caregivers” (Lau & Au, 2011). However, family members, especially spouses of persons with PD, often react negatively to the label “carer” or “informal caregiver.” Instead, spouses perceive the support they provide as merely an extension of the marital relationship (Habermann, 2000). Hence in the present study, family members who provide care for persons with PD are referred to as the *loved ones providing care*.

Given the progressive nature of the disease, the PD caregiving role usually unfolds slowly and over a long period of time (Dyck, 2009). The caregiving role emerges from the existing relationship role (e.g., wife, husband, daughter, or son) and gradually transitions to a caregiving role (Montgomery & Kosloski, 2009). In PD caregiving, as the disease progresses and the person with PD’s functioning declines, loved ones begin to perform caregiving

activities that have not previously been part of their familial role. For example, a loved one may take on the task of managing finances if the person with PD is frequently confused and struggling to concentrate long enough to engage in this previously performed role responsibility. Then, with increasing disability, caregiving activities begin to extend substantially further than the scope of the original familial role.

Consequently, these loved ones are required to change their role identity which involves not only changing their behaviours but also the way they perceive their role with regards to the care-receiver (Montgomery & Kosloski, 2009). Loved ones are required to accept that the dynamics and role responsibilities within their relationships will never be the same again. Moreover, they are required to accept that they will assume the role of primary caregiver.

PD has the potential to deprive persons with PD of their dignity, self-confidence, sense of self-worth and meaning (Frazier, 2000) because over time they are forced to relinquish personal and role responsibilities (Hely et al., 2005). These roles may have been integral to a person with PD's identity and sense of meaning prior to the debilitating impact on his or her functioning.

Typically, not only does it become increasingly difficult for persons with PD to provide their loved ones with physical support (i.e., performing household tasks or driving responsibilities), but also their ability to provide emotional and psychological support is diminished (Blanchard, Dosser, Hodgson, & Lamson, 2009; Chiong-Rivero et al., 2011; Ramig, Fox, & Sapir, 2008) because of the impairments in both verbal and non-verbal communication arising from the disease's pathology. Firstly, in terms of verbal communication, talking and engaging often becomes effortful, tiring, and frustrating for persons with PD. As a result, persons with PD often become less inclined to initiate communication and interact with those that share their lives (N. Miller, Noble, Jones, &

Burn, 2006). Secondly, in terms of non-verbal communication, the *facial mask* or *stone-face* (Pell & Monetta, 2008) makes it difficult to communicate their deepest feelings and thoughts to those around them (Chiong-Rivero et al., 2011). The facial mask is a common PD feature characterised by loss of facial expression which manifests in a moody, depressed or emotionless appearance (Jankovic, 2008). If a person with PD's symptoms manifest in the facial mask, he or she lose the ability to reassure or put a worried loved one at ease with a simple knowing look, facial expression, or gesture. Hence, impairments in both verbal and non-verbal communication can have substantial negative impacts on the loved ones of persons with PD, especially those who provide care, who may ultimately feel unsupported, isolated, alone, and unappreciated (McRae et al., 2009; N. Miller et al., 2006; Pasetti et al., 2003).

The transition from a shared-responsibility or mutual caregiving relationship between two loved ones, to a one-sided, dependence-oriented relationship between a caregiver and a care-receiver can be fraught with tension and conflict (Hodgson, Garcia, & Tyndall, 2004). This is often due to role reversal problems, especially when the caregivers' role responsibilities conflict with previously held roles (Coombs, 2007; Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011; Tan, Williams, & Morris, 2012). It has been suggested that the transition from a familial relationship to a caregiver-care-receiver relationship is harder in PD caregiving compared to dementia caregiving (Davis et al., 2011; Sanders-Dewey, Mullins, & Chaney, 2001). Davis et al. (2011) investigated the impact of dementia on spousal relationships and compared this to the impact of PD on spousal relationships. Findings showed that PD caregivers were more likely to report conflict and tension when trying to assist and provide care for the care-recipient. This finding was supported by persons with PD attempting to remain independent for as long as possible, through actively seeking to manage their own care and problem-solve for themselves. In these instances,

persons with PD often challenged caregivers' strategies and resisted caregivers' efforts to help, which in turn led PD caregivers to feel as if their efforts to help were not appreciated or not respected by the person with PD. As a result, this contributed to feelings of dissatisfaction, conflict and tension within the couples' relationship.

The unpredictable and changeable nature of PD can further complicate the changing role transitions, and adds to the complexity of providing care for persons with PD. Motor symptoms constantly fluctuate on a daily, sometimes hourly basis, and in some cases from minute-to-minute because of the effects of medication (Ozdilek & Gunal, 2012). During "on periods" when medication is effective, little help is required because the person with PD can function relatively normally. During "off-periods" when the person with PD's functioning is significantly impaired, he or she may be almost completely dependent on caregivers for assistance with daily functioning. Thus, loved ones providing care are required to frequently change and adapt the level of care provided to meet the needs of persons with PD depending on their level of functioning at any given time (Dyck, 2009; Ozdilek & Gunal, 2012; Waite, 2000). Loved ones providing care may find it difficult to plan daily activities around these symptom fluctuations and the strict medication regime, which in turn can result in a sense of loss of independence and control over their lives (Edwards & Scheetz, 2002; Roland, Jenkins, & Johnson, 2010; Wressle, Engstrand, & Granérus, 2007).

Typically, the loved one providing care becomes an integral member of the person with PD's health care team (McLaughlin et al., 2011; Secker & Brown, 2005), and there is evidence that having a caregiver is associated with maintaining independent living, having a better quality of life, as well as delayed nursing home placement for a person with PD (Deloitte Access Economics, 2011; Martínez-Martín et al., 2005). Therefore, loved ones providing care play a large economic role in reducing health care costs (Hempel, Norman, Golder, Aguiar-Ibáñez, & Eastwood, 2008; Roland et al., 2010). Informal caregivers are

estimated to provide some \$30 billion (AUD) support annually to people with disabilities in Australia alone, representing one-fifth of the health-care cost of nursing home placement (Access Economics, 2011). Thus, despite the difficulties with role transition and dealing with the challenges imposed by the nature of the disease, loved ones often remain committed and dedicated to the caregiving role until the death of their persons with PD (Access Economics, 2011).

It is widely acknowledged that informal caregiving is the most effective and efficient way to care for persons with PD (Access Economics, 2011). Yet, despite these benefits for persons with PD and the economy, caregiving can come at a cost to caregivers. Caregiving, in general, can have detrimental consequences on the caregivers' physical (Beach, Schulz, Yee, & Jackson, 2000; Rozanski, Blumenthal, Davidson, Saab, & Kubzansky, 2005) and mental health (Pinquart & Sörensen, 2004), and in turn can lead to diminished quality of life for the loved ones providing care (Clarke, Zobkiw, & Gullaksen, 1995; Kelly et al., 2012; O'Connor & McCabe, 2011; Tew, Naismith, Pereira, & Lewis, 2013; Zhao et al., 2010).

1.3 Negative Effects of PD Caregiving

It is well recognised in the literature that providing care for persons with PD can be stressful, burdensome, (Caap-Ahlgren & Dehlin, 2002; E. Miller, Berrios, & Politynska, 1996; O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996) and even traumatic (Arber & Venn, 2011; Williamson, Simpson, & Murray, 2008). The loved ones providing care for persons with PD have to contend with not only the motor symptoms, but also the non-motor symptoms that accompany the disease. Several studies have shown that non-motor symptoms (i.e., depression, psychosis, falls and sleep disturbance) comparative to motor symptoms have a greater impact on the loved ones when assessed by burden, depression, and quality-of-life measures (Chaudhuri et al., 2006; Forjaz et al., 2011; Secker & Brown, 2005).

There is also consistent evidence that loved ones providing care for persons with PD perceived that the emotional side of caregiving is harder to cope with than the physical side of caregiving (Aarsland et al., 2007; Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Caap-Ahlgren & Dehlin, 2002). For example, Roland et al. (2010) discovered that the majority of PD caregivers found the physical consequences of their person with PD falling (e.g., picking the person with PD up off the ground) was less burdensome than the emotional consequences of falling. In PD, there is an increased risk of falls as the disease advances because coordination and level of physical functioning declines (Hely et al., 2005; Jankovic, 2008). Roland et al. (2010) found that these PD caregivers felt they were “always on guard” and “constantly watching and worrying” in case their person with PD fell or had an accident. These loved ones providing care for persons with PD described the relentless and ongoing vigilance as “mentally exhausting” because they were constantly reminding and cueing their persons with PD how to safely perform tasks (e.g., walking). These loved ones were also worried that their actions and reminders caused the persons with PD to become increasingly aware of his or her deterioration and diminishing independence.

Hence, loved ones providing care are faced with “a double emotional dilemma” (Chiong-Rivero et al., 2011), that is, not only having to deal with the person with PD’s emotional needs and reactions to the disease (e.g., depression, frustration, fear and anxiety about loss of independence and autonomy), but his or her own emotional needs and reactions to changes imposed by the disease. The PD caregiving experience is thus generally typified by uncertainty, frustration and a profound sense of loss, as well as guilt from the onset of the presence of PD in their lives to post-caregiving situation.

Frustration with the disease is commonly reported by persons with PD (McKinlay et al., 2008; Welsh, 2004; Zesiewicz et al., 2006) and vicariously by the loved ones providing care (Chiong-Rivero et al., 2011). Habermann (2000) found that one of the hardest aspects

of the caregiving experience for middle-aged spouses was watching their person with PD struggle and become frustrated with the disease. They found it difficult to witness the gradual decline in the person with PD's ability to perform everyday tasks that once came naturally, as well as the inability to continue in employment, and to fulfil interests, hobbies, and social activities.

Moreover, the PD caregiving situation, and in some cases post-caregiving, has been described by loved ones providing care as "traumatic". Traumatic experiences include: witnessing psychotic episodes and hallucinations (Williamson et al., 2008); dealing with the emotional and physical consequences of falls (Davey et al., 2004); the side effects of long-term medication, such as dyskinesia (Frazier, 2000; Politis et al., 2010); dealing with the changes in the person with PD's personality and behaviour during the aftermath of treatment by deep brain stimulation (DBS) surgery (StraitsTroester et al., 2000); the anguish and trauma that comes with placing their loved one in a nursing home (Carter, Lyons, Lindauer, & Malcom, 2012; Goldsworthy & Knowles, 2008); and ultimately the death of their loved one with PD (Carter et al., 2012; Lau & Au, 2011; Seltzer & Li, 2000).

To date, most of the PD caregiving research has focused on the negative aspects of PD caregiving. Within this, considerable attention has been paid to caregiver burden (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Lokk, 2008; Razali et al., 2011). Caregiver burden is defined as the degree to which the caregivers' perceived mental, emotional and physical health, social life and financial status suffer as a direct result of their caregiving experience (Roland et al., 2010).

Numerous PD studies have found that caregiver burden is experienced across all stages of PD, and as the disease advances the loved ones providing care report higher levels of burden, compared to early stages of PD (e.g., Cifu et al., 2006; K. S. Kim et al., 2007; Martinez-Martin et al., 2008). For example, Carter et al. (1998) found a strong and

significant association between advancing stages of PD and increasing levels of burden reported by the loved ones providing care. Perhaps this is unsurprising, given the progressive nature of PD as loved ones providing care are not required to deliver much physical support and assistance during the early stages of the disease. What these findings indicate is that the loved ones providing care for persons with PD can expect to experience increased burden as the disease progresses.

There is a predominance of positivist and post-positivist focus within PD caregiving research, and therefore most of the studies have adopted a quantitative design framework. Researchers have typically used quantitative research methods to investigate the contextual (i.e., social support, severity of the disease, quality of relationship), and personal (e.g., caregiver age, ethnicity, personality, self-efficacy) factors that may predict negative outcomes of PD caregiving. These outcomes include burden, depression, diminished quality of life and poorer health outcomes for PD caregivers. Establishing a better understanding of what aspects of the disease and caregiving lead to substantial caregiver burden and stress have been used to inform clinicians working with this population so that they can better design tailor-made interventions and support programs for caregivers. These programs are aimed at ameliorating the negative effects of caregiving, as well as enhancing caregivers' well-being, and their effectiveness and ability to cope in the PD caregiving role (Lau & Au, 2011).

These caregiving studies have been largely grounded in the *stress and coping model* (Lazarus & Folkman, 1984). The stress and coping model posits that stress during caregiving will occur if the caregiver perceives there is a discrepancy between the perceived demands (e.g., caregiving tasks) of the caregiving situation, and the resources (e.g., social support or self-efficacy, knowledge and experience) available to the caregiver. That is, the greater appraised discrepancy, the greater the subjective experience of stress (Lazarus & Folkman,

1984). However, adopting this model conceptualises caregiving as a negative experience typified by stress and burden, and does not lend itself easily to view caregiving as a positive experience.

1.4 Positive Effects of Caregiving

Research suggests that there can be positive effects of providing care for an elderly relative (Berg-Weger, Rubio, & Tebb, 2001; Lopez, Lopez-Arrieta, & Crespo, 2005; Louderback, 2000), or for a relative with a chronic illness such as dementia (Carbonneau, Caron, & Desrosiers, 2010; Farran, Miller, Kaufman, Donner, & Fogg, 1999; Tarlow et al., 2004). For example, Cohen, Colantonio, and Vernich (2002) found that 73% of family caregivers providing care for an elderly relative identified at least one positive experience associated with caregiving, and 6.9% identified more than one positive feeling. Caregivers reported that caring for an elderly relative provided a sense of satisfaction, companionship, enjoyment, a fulfilled sense of duty or obligation, and gave a sense of meaning or importance. Results revealed that these positive experiences were associated with lower depression scores, lower burden scores and better self-assessed health. It was concluded that such positive experiences could ameliorate the negative effects of caregiving.

With the growing acknowledgement of the positive experiences of caregiving, Folkman (1997) reworked the original model of stress and coping (see Lazarus & Folkman, 1984) to encompass more positive aspects and meaning-focused coping (see Folkman, 1997). However, there has been little research to date on the positive experiences and growthful development associated with PD caregiving. There are a small number of studies that have recognised that there can be positive effects of providing care for persons with PD (Chiong-Rivero et al., 2011; Habermann, Hines, & Davis, 2013; Williamson et al., 2008). However, these authors acknowledged that the positive effects were not sufficiently explored in their

studies because the negative effects were the primary focus of this research. These studies will be discussed in more detail in Chapter Two.

There is currently no published research (that the author is aware of) that has focused on the lived experience that gives primacy to the positive experiences of PD caregiving. There are numerous studies that have adopted a strengths-based perspective (Saleebey, 2012) to investigate the positive aspects of dementia caregiving, but not PD caregiving (e.g., Peacock et al., 2010; Rapp & Chao, 2000; Saleebey, 2012). The strengths-based perspective moves beyond the emphasis of problems and burden, and views caregiving as a source of opportunity for building strength, as well as personal and relationship growth (Peacock et al., 2010). Embedded within the strengths-based perspective is the view that any individual is capable of positive change and growthful development, and that any individual can be supported to attain insight into their personal strength and resources (Saleebey, 2012).

This study adopts a strengths-based perspective to investigate PD caregiving. In doing so, this study does not ignore, nor de-value, the negative aspects that are often associated with PD caregiving. Rather, this study is concerned with emphasising, or bringing to the fore, that the PD caregiving situation has potential to provide an opportunity for positive psychological changes and growthful development within the challenges that PD caregiving often presents.

1.5 Rationale

Despite the possibility of caregiving in general being a positive experience, this topic remains relatively under-researched in the PD caregiving literature. While much attention has been given to the negative impact of providing day-to-day care for persons with PD, little is known about the positive experiences and growthful development that the loved ones providing care perceive, and the possible positive impacts it may produce upon their lives (i.e., personal and relationship growth). General caregiving literature shows the gains

consequential from the caregiver role are conceptually distinct from the widely recognised strains associated with caregiving, and that predictors of positive and negative aspects of caregiving are often not the same (Al-Janabi, Frew, Brouwer, Rappange, & Van Exel, 2010; Kinney & Stephens, 1989; Rapp & Chao, 2000). Due to these differences, Kramer suggests that the negative experiences and positive experiences need to be studied separately, and more in-depth research into the positive side of PD caregiving is required. Furthermore, due to differences in the negative effects of caregiving found across various caregiving populations, it can be deduced that results investigating either positive or negative experiences of other chronic diseases cannot be generalised to PD carers. For example, one study found a weak association between burden and dementia but a strong association between burden and PD and burden and stroke (Thommessen et al., 2002). Goldsworthy and Knowles (2008) emphasised that there are unique factors and concerns associated with PD caregiving compared with the caregiving associated with other disorders, such as dementia and cancer. In consideration of these points, the overarching aim of this research was to elucidate the relatively unknown nature of the positive experiences of loved ones providing care for PWP, with respect for the fact that caring for a loved one with PD presents its own unique set of obstacles as well as opportunities towards growth-ful development. The nature of how PD may differ in regards to opportunities towards growth as compared to other chronic diseases is explored, as follows.

1.5.1 Differences between PD caregiving and other chronic disease populations.

Whilst the potential for positive psychological changes and growth-related development has been found in other caregiving populations, this research cannot necessarily be generalised to the PD caregiving situation because the nature of PD poses different challenges and concerns than other illnesses or disorders (Goldsworthy & Knowles, 2008; Thommessen et al., 2002). Park (2009) asserts that the nature of a disease or health condition poses specific and unique

challenges and concerns for those directly affected by the disease or health condition.

Disease-specific factors include: the pattern of symptom onset, diagnostic experience, prolonged diagnosis, aetiology, disease trajectory, impacts and disruption to life, and life context. Park (2009) argues that in turn, these disease-specific factors are likely to influence levels and types of self-perceived growthful development in those directly affected by a medical condition. Based on these assertions, it may also be that disease-specific challenges and concerns also impact those indirectly affected by the disease or health condition, such as loved ones or caregivers, and in turn the levels and types of growthful development.

For example, providing care for persons with PD is likely to present different challenges and take on a different meaning to providing care for a “cancer survivor”. There are numerous studies that have investigated positive psychological changes and growthful developments in the aftermath of a cancer diagnosis (e.g., Manne et al., 2004; Moore et al., 2011; Weiss, 2004). However, these samples comprised cancer survivors who were diagnosed with early stage breast cancer, with a good prognosis. The diagnosis experience may be substantially different to having a loved one diagnosed with PD, as well as the caregiving situation and context for loved ones of cancer survivors, and providing care for a loved one with PD compared to providing care for a loved one with breast cancer. For instance, having a loved one diagnosed with early stage breast cancer with a good prognosis is likely to be different and take on a different meaning compared to having a loved one diagnosed with PD, which is an incurable, degenerative disease, with essentially unknown aetiology and heterogeneous prognosis.

Further, cancer caregiving studies have found that care-recipients’ expressing gratitude for the caregiver’s efforts through “a smile or a wink” was a determinant of the positive experiences associated with cancer caregiving, where caregivers reported a sense of accomplishment from being able to help their loved ones with cancer (Li & Loke, 2013). In

contrast to providing care for a cancer patient, if a person with PD's symptoms manifests in the facial mask, apathy and anhedonia, they may appear disinterested, disengaged, apathetic and possibly ungrateful. These non-motor symptoms may have implications for the loved ones providing care, because they may feel largely ignored and unappreciated, or feel like they are always initiating tasks or constantly encouraging the person with PD to do things. This may result in feelings of disappointment or frustration within the relationship, rather than positive experiences such as feelings of accomplishment and appreciation. This elucidates the need for further research into the positive experiences specifically for PD caregivers, in contrast to other caregiving populations.

A review of the research exploring caregivers' experiences across various life threatening diseases suggests significant differences in regards to the caregiver experiencing positive psychological gains or personal development according to the degree of threat to the life of their loved one that each disease or disease stage proposes. A greater threat leads to more opportunity for personal development. Research has consistently found that the degree of threat to life is a predictor of positive psychological changes and growth-ful development (Park, 2009). Numerous studies (e.g., Manne et al., 2004; Moore et al., 2011; Weiss, 2004) have shown that a life-threatening disease diagnosis has been associated with positive psychological changes and growth-ful development, not just for the patient but also the loved ones or caregiver. The realisation of a shortened life span and impending mortality has been shown to provide impetus for positive psychological changes and growth-ful development (i.e., new found appreciation for life and impetus to make the most of life). Again, not just in patients but in HIV caregivers (Cadell, 2003, 2007), the loved ones of stroke survivors (Bacon et al., 2009; Hallam & Morris, 2013) and the loved ones of cancer survivors (Manne et al., 2004; Moore et al., 2011; Weiss, 2004).

Life limiting diseases (such as PD) pose a lower degree of threat to one's life at the time of diagnosis compared to life threatening diseases such as terminal cancer (Park, 2009). Park (2009) asserts that the greater threat to life, the greater accompanied distress, and in turn the greater need for cognitive coping (meaning-making processes) that lead to self-perceived psychological change and growth-ful development amongst persons affected and their loved ones providing care. Therefore, because PD is a life limiting rather than life threatening disease, PD caregivers may be less likely to experience growth-ful development when helping PWP, as compared to carers who are looking after sufferers of more life-threatening diseases because the impending mortality is less imminent. This explains just one other possible way in which persons with PD and their caregivers' experiences may differ from those with other chronic diseases. Hence, further investigation focusing on the self-perceived positive psychological changes and growth-ful development specific to loved ones providing care for persons with PD is warranted, and is the contribution of this study to the general caregiving domain.

1.5.2 A strengths-based approach versus a deficits-based approach. Research from a strengths-based perspective is warranted because the lack of acknowledgment of the positive experiences and growth-ful development in PD caregiving potentially skews perceptions of the PD caregiving experience to be overly negative without acknowledgement of caregivers' strengths. Understanding what encourages resilience and positive experiences amongst PD caregivers can help direct therapeutic intervention to promote these sources of positive outcomes in assisting caregivers' adjustment difficulties.

The deficits-based view that has largely been adopted in PD caregiving literature tends to imply that PD caregiving has only negative and detrimental effects on the overall well-being of loved ones providing care for persons with PD. This deficits-based perspective leads to a focus on deficits-based practice interventions to alleviate the negative experiences

associated with PD caregiving. The positive psychology approach to therapy emphasises facilitation of adjustment via the identification and mobilisation of clients' strengths. In accordance with principles of a positive psychology therapeutic approach, a focus on reducing negative symptomology can create a barrier for the practitioner in assisting caregivers' adjustment difficulties in the following way: Reinforcement of the client's identification with the strains of caregiving can occur, increasing focus on burden and feelings of hopelessness, whilst identification and strengthening of personal developments gained from the caregiving role can become overlooked. The ability of the caregiver to personally identify with positive self attributes, values, hopes and aspirations garnered from the caregiving experience is arguably essential to positive adjustment (Saleebey, 2012). Also, a negatively biased representation of the caregiving experience fails to encapsulate the true nature of both caregiver and persons with PD in regards to personal resources to create positive meaning from hardship. In short, the outstanding capacity of the human condition is to foster hope in the face of immense hardship. A greater understanding of sources of positive growthful development can be used to inform practitioners of where and how they can facilitate a shift in a negative outlook to a more positive outlook within their clients.

Moreover, it is important to focus on the positive side of PD caregiving, not only because experiencing growth is valuable in its own right, but also because the experience of growth (e.g., deriving pleasure, deriving new skills, finding meaning and a sense of gratification) may buffer against the detrimental consequences of caregiving (e.g., burden, depression, health problems and quality of life). Positive psychological changes and growthful development are also important because maintaining and sustaining optimal psychological, emotional, and social well-being for the loved ones providing care is paramount, for not only personal caregiver benefits, but for benefits to their persons with PD. Pakenham and Cox (2008) found that self-perceived positive psychological changes and

growth-ful development in multiple sclerosis (MS) caregivers had positive implications for care-recipients' adjustment to the disease. Arguably the caregiver's ability to identify growth-ful development in one self is an aspect of resilience to hardship, permeating the caring role across various chronic diseases. Therefore, based on Pakenham and Cox's research it can be deduced that persons with PD who have caregivers who can identify positive psychological gains from the caregiving experience would also experience benefits, much like those suffering with MS.

Through deriving positive experiences and growth-ful development(s) the loved ones providing care for persons with PD may become better and more effective caregivers. Being a better and more effective caregiver may improve the prognosis, health outcomes of persons with PD, and slow the rate of decline of the disease, as well as ultimately improve quality of life for both persons with PD and the loved ones providing care. It may also be that if a caregiver derives a sense of fulfilment, enjoyment and satisfaction from caregiving they are more likely to remain committed in the caregiving role and prevent nursing home placement prematurely, and therefore reduce health care costs. Increased knowledge and understanding of the PD caregiving role and its positive experiences are therefore warranted, with the view to informing positive psychological interventions aimed at enhancing positive experiences. Although deriving positive psychological gains from the caregiver experience has benefits for the sufferer arguably across different chronic diseases, the exact nature of these positive psychological experiences cannot be generalised from MS research to persons with PD due to the specific nature of PD and the associated challenges it poses, hence the need for this research.

1.6 Purpose, Aims, and Research Question

The purpose of this study is to capture the lived experience of loved ones providing care for persons with PD. As such, both the negative and positive experiences are likely to

be elicited. However, to reiterate, this study is concerned with bringing to the fore, the possible positive experiences within the challenges that often come with providing care for a loved one with PD. Given the descriptive nature and the qualitative methodology adopted by the proposed study, there are no specific or predetermined hypotheses as is common with quantitative studies. Instead there are four aims that will be investigated.

- 1) To elucidate the loved one's lived experience of providing primary care for a family member with PD.
- 2) To explore whether the loved one's report self-perceived positive experiences and growth-ful development(s) associated with PD caregiving.
- 3) The third aim is dependent on the results associated with first and second aim. That is, after establishing whether positive experiences and growth-ful developments associated with PD caregiving were present or not; the third aim is to elucidate how the loved ones positively make-sense and ascribe positive meaning to the experience of having a loved one diagnosed with PD and the PD caregiving situation.
- 4) To examine ways in which findings support and contribute to existing growth theories in the context of PD caregiving literature.

The present study's research question is to identify whether the loved ones providing care for persons with PD report self-perceived positive psychological changes and growth-ful development(s) through positively making-sense and ascribing positive meaning to the PD caregiving experience.

Chapter Two: Theoretical Framework

The purpose of this chapter is to describe the psychological theoretical frameworks that underpin the present study, and to make explicit the theoretical assumptions of this study. This chapter will first focus on three growth theories/models that inform the present study's theoretical frame, which are: (1) the revised meaning-making model (Park, 2010), (2) the Adversity-Activated Development theory (AAD) (Papadopoulos, 2007), and (3) the post-traumatic growth theory (PTG) (Tedeschi & Calhoun, 2004). A general overview of each theory/model will be followed by the particular assumptions or conceptualisations informing this research and an explanation as to why proponents from each theory were adopted within the context of investigating PD carer's positive experiences and growth-ful development.

2.1 Theoretical Frameworks of Growth-ful Development

2.1.1 Revised meaning-making model. The revised meaning-making model (Park, 2010) is illustrated in Figure 1, and each aspect of the model is outlined below. This model is based on commonalities of the most influential growth-related theories, which include (but are not limited to) earlier meaning-making models (Folkman, 1997, 2008), and PTG theory (Tedeschi & Calhoun, 2004). Park (2010) identified that although influential growth theories differed on some particulars in terms of their theoretical viewpoints, there is a high degree of consensus with regards to explaining growth-ful development following stressful and/or traumatic situations, events or experiences. Based on this consensus, the revised model proposes to explain the underlying cognitive processes necessary for positive psychological change and growth-ful development following potentially stressful situations, events, or experiences. Given this model most comprehensively explains these underlying cognitive processes; it informs the present study's theoretical frame.

Figure 1. The revised meaning-making model

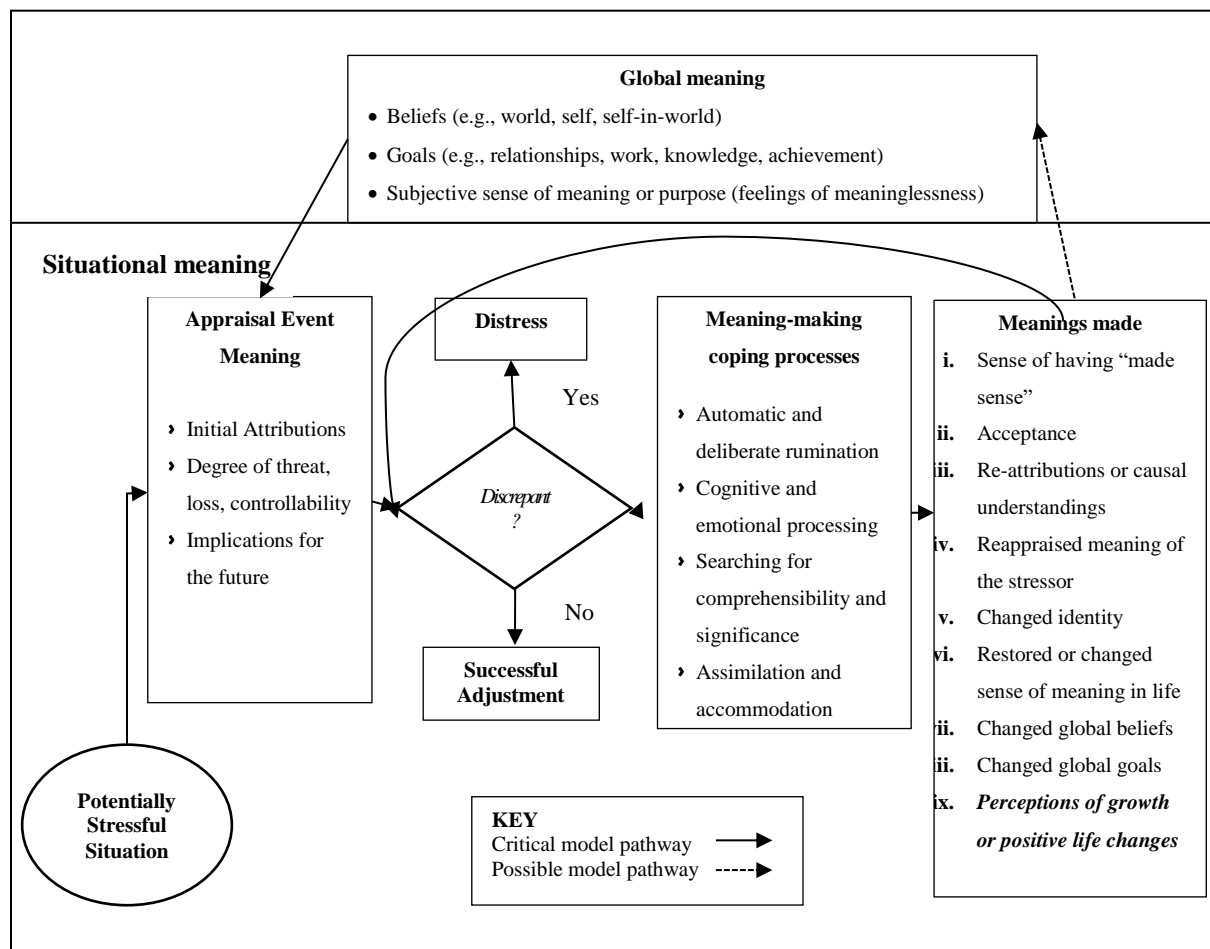


Figure 1. Meaning-making model (Park, 2010). Adapted from “Making Sense of the Meaning Literature: An Integrative Review of Meaning Making and Its Effects on Adjustment to Stressful Life Events,” by C. L. Park, 2010, *Psychological Bulletin*, p. 258

Potentially stressful situation. The starting point, or foundation, for positive psychological change and growth-ful development is the initial appraisal of the potentially stressful situation, event or experience. The potentially stressful experience must be perceived by an individual, in this instance a caregiver, as sufficiently threatening to the order of one’s life for the activation of meaning-making coping processes implicated for growth-ful development. That is, it is the appraisal or perception of the event being stressful, rather than the event or situation itself. This idea underpins most growth theories including PTG and AAD.

Appraisal event meaning. The initial appraisal of an event's meaning involves a variety of factors such as "the extent to which the event is threatening and controllable, initial attributions about why the event occurred, as well as the possible implications for one's future" (Park, 2010, p. 259). Significant adverse life events (e.g., having a loved one diagnosed with a life-threatening disease or the death of a loved one) often present major challenges and contradictions to an individual's assumptive world (Janoff-Bulman, 2004; Park, 2010). The assumptive world refers to everything one knows or thinks they know about the world (Parkes, 1971). When an individual's assumptions or global beliefs about justice, coherence, benevolence, predictability, and controllability of the world, or one's safety, identity and future are challenged, threatened or contradicted, this triggers a state of heightened anxiety, distress, and a sense of meaninglessness (Park, 2010; Calhoun, Cann, & Tedeschi, 2010; Tedeschi & Calhoun, 2004).

For example, a caregiver may hold the global belief that "the world is fair and just," and "good things happen to good people, and bad things happen to bad people." When a loved one is diagnosed with an incurable and terminal disease such as PD, with an unfavourable outcome, this is likely to violate the caregiver's pre-existing beliefs about the world, because something "bad" has happened to the person they love, a person whom he or she considers inherently "good." Thus, the event challenges pre-existing beliefs or assumptions about the world being "fair and just." It is the violation or shattering of the assumptive world (or global beliefs) that activates the meaning-making processes necessary for growth-ful development (Park, 2010).

Discrepancy between appraised and global meaning. After appraising an event, individuals determine whether the appraised (or situational) meaning matches or contradicts their *global meaning*. Global meaning refers to an individual's global beliefs, goals, and sense of meaning (Park, 2010). *Global beliefs* are comprised of assumptions or broad views

about “control, predictability, coherence” and so forth as well as “self-views” or beliefs (Park, 2010, p.258). *Global goals* are “internal representations of desired outcomes”, such as good health, relationships with loved ones, knowledge acquisition, and personal as well as professional achievement (Park, 2010, p. 258).

Consequently, perceptions of discrepancy, such as “one’s sense of the controllability or comprehensibility of the world, are thought to create the distress” that activates meaning-making coping efforts (Park, 2010, p. 259). The “extent of discrepancy between the appraised meaning of the event and the individual’s global meaning is thought to determine the level of distress experienced” (Park, 2010, p. 259). In other words, the greater the distress experienced by a caregiver, the greater the need to employ meaning-making processes, and ultimately the greater the self-perceived positive psychological changes and growth-ful development.

Meaning-making coping processes. Meaning-making processes can include both *cognitive* and *emotional processes*, employed to reduce heightened states of distress and meaninglessness as a result of the appraised stressful, adverse or traumatic life event. That is, the aim of these cognitive processes is to reduce the discrepancy between appraised situational meaning and global meaning. Cognitive and emotional processing are widely considered essential for adjusting to stressful or traumatic life events (Park, 2010).

Cognitive processing. During cognitive processing, *automatic* and *intrusive rumination* transforms into more effortful and *deliberate rumination* (Calhoun, Cann, & Tedeschi, 2010; Tedeschi & Calhoun, 2004). Automatic and intrusive rumination are characterised by frequent and recurrent thoughts about the trauma and related issues (Calhoun, Cann, & Tedeschi, 2010). In contrast, deliberate and constructive thinking are characterised by more effortful cognitive processes and can involve analysing the new situation (e.g., loved one receiving a diagnosis of a life-threatening illness), searching for

possible causes and solutions to the problem (e.g., seeking a cause for the disease and researching treatments); searching for reasoning (e.g., questioning why their loved one was diagnosed with a terminal illness, such as “what did he or she do wrong to deserve the diagnosis?”); sense-making and searching for and finding meaning (e.g., reframing the diagnosis as a reminder that life is finite, and to make the most of each day), and anticipating the future (e.g., thinking about the event will impact the caregivers’ life) (Leipold et al., 2008).

Emotional processing. Emotional processing involves effortful attempts to understand what one is feeling (Sears, Stanton, & Danoff-Burg, 2003) or more specifically the emotional reaction evoked by the stressful, adverse or traumatic event in an individual (Park, 2010). For example, the shock and uncertainty that often accompanies the PD diagnosis. Emotional processing includes either delving into the meaning of feelings to understand the emotions that accompany the diagnosis; or by emotional expression, where one talks about emotions and thoughts with others (Park, 2010; (Calhoun, Cann, & Tedeschi, 2010).

Assimilation and accommodation. Park (2010) posits that either global meaning or appraised meaning has to change for a reduction in discrepancy, and ultimately distress and a sense of meaninglessness. *Assimilation* refers to the “meaning-making process that involves changing situational appraised meaning to be more consistent with existing global meaning” (p.260). In contrast, *accommodation* refers to the meaning-making process that involves changing global meaning, beliefs, goals or identity to be more consistent with the context or situation (Joseph, 2011; Park, 2010).

Outcomes of meaning making-processes. Park (2010) describes the distinction between meaning-making processes and outcomes of meaning-making processes as *meanings-made*, which refers to the products or the outcomes of meaning-making processes.

Meanings-made are “end results or changes derived from attempts to reduce discrepancies or violations between appraised and global meaning” (p.260). The various types of meaning-made (see Figure 2) include:

- (i) *Sense of having “made sense.”* This refers to an individual’s self-report about having “made sense” of an adverse event, situation or experience. Park (2010) asserts that having “made sense” is an outcome of psychological processes such as sense-making, searching for reasoning, and searching for comprehensibility. Each is a form of cognitive restructuring and reappraisal in order to come to terms with the adverse life event. Park also states that having “made sense” is the most common type of meaning-made reported by individuals in the aftermath of adversity.
- (ii) *Acceptance.* This refers to the extent to which individuals report having achieved a sense of acceptance or coming to terms with a stressful or traumatic event (Park, 2010).
- (iii) *Reattributions and causal understanding.* Several growth-theorists have proposed that an individual’s understanding of the cause of an adverse event, situation, or experience is an important type of meaning-made (e.g., Janoff-Bulman, 2004). Attributions about the cause of an event are considered reattributions because they are likely to have undergone considerable alteration since the initial attribution of the event when it first occurred (Bonanno, 2004).
- (iv) *Reappraised meaning of the stressor.* This type of meaning-made refers to the process where individuals transform the appraised meaning of an event, rendering it less noxious and more consistent with pre-existing beliefs, goals and desires. Individuals, therefore, come to reappraise the event’s implications

or meaning in more positive ways (Park, 2010). For example, a caregiver may come to positively reappraise the caregiving situation as an opportunity to spend time with his or her person with PD.

- (v) *Changed identity.* Changed identity, or the integration of the stressful experience into one's identity is viewed as an outcome of both assimilation and accommodation. Changed identity involves identity reconstruction or the shifting of one's personal biographical narrative as a result of the stressful or traumatic experience (Park, 2010). For example, through accommodation a loved one changes their role identity from a loved one to a primary caregiver.
- (vi) *Restored or changed sense of meaning in life.* Similar to benefit finding, finding meaning is concerned with the event's significance on an individual's life. Restored or changed sense of meaning is an outcome of searching for significance (Park, 2010).
- (vii) *Changed global beliefs.* In addition to resolving discrepancies by changing appraised meaning, individuals make changes to their global beliefs following adversity (Park, 2010). For instance, when a loved one is diagnosed with a life-threatening disease, this confrontation with death or shortened life arouses anxiety in both those directly affected as well as their caregivers, leading to awareness in their own existence and mortality. In this instance, an example of changed global belief may involve coming to see life as more fragile (Peacock et al., 2010).
- (viii) *Changed global goals.* "Meaning-making can also result in identifying goals that are not attainable and abandoning them or substituting them for alternative goals" (Park, 2010, p.261). There are many instances of people experiencing adverse situations, and subsequently go on to devote their lives

to the related cause (Park, 2010). For example, an individual (survivor) who causes a fatal accident as a result of driving intoxicated, goes on to raise public awareness of the consequences of drink-driving as a way of coping with the event.

- (ix) *Perceptions of growth and positive life changes.* Park (2010) conceptualises perceptions of growth and positive life changes as an outcome of meaning-making processes (see Figure 1). This concept is the same as ADD and PTG, and is most relevant to the present study because it is concerned with positive psychological changes and growth-ful developments as a result of providing care for persons with PD.

2.1.2 Adversity-activated development theory. AAD theory was developed by Papadopoulos (2007) based on investigations of refugees following their forced relocation to another country as a result of political and/or military action in their country of origin. Papadopoulos found that when the refugees were exposed to adversity, three possible responses emerged: (1) a negative or stress response, (2) a neutral response, and/or (3) a positive response. AAD theory maintains that response to adversity is not limited to being traumatised (negative or stress response), but can include resilience (neutral response) and adversity-activated development (positive response).

The stress or negative response to the exposure of adversity is common, and can have varying levels of severity and duration. Papadopoulos (2007) identified three degrees of severity, which range from a normal stress response to a psychological disorder. The first negative response is the normal stress response, where an individual may experience stress-related symptoms for a relatively short period of time, typically for up to two weeks, following the adverse event, situation or experience. These stress-related symptoms may include physical symptoms (e.g., teary, heightened sense of arousal or unease, and agitation),

cognitive symptoms (e.g., ruminatory thoughts about the event, trying to make sense of the event, and worry about the future), and behavioural symptoms (e.g., difficulty sleeping, withdrawal, and avoidance behaviours such as increase in alcohol consumption).

Typically, individuals have the ability to process adversity within the context of a healthy philosophy of life and with social support. As a result, these stress-related symptoms subside within a relatively short period of time. The second negative response is more severe than the typical stress response; it involves a stronger or more heightened experience of discomfort. The stress-related symptoms are greater in frequency, intensity and duration compared to the normal stress response. This response is not uncommon, and typically can be dealt with effectively without any psychological intervention. The third negative response is a psychological disorder, which is the most severe negative consequence of exposure to adversity and requires psychological intervention. The most common disorder is post-traumatic stress disorder (PTSD) in accordance with the American Psychiatric Association's diagnostic and statistical manual of mental disorders (APA, 2000) diagnostic criteria.

According to Papadopoulos (2007), the second possible response to the exposure of adversity is resilience. Resilience is considered a neutral response to stressful and traumatic experiences and situations because the key characteristic of resilience is that it retains qualities that existed before the exposure to adversity, which suggests coping with the event. Whereas AAD (the third response) is considered a positive response because it is characterised by the emergence of positive psychological changes and growth-ful developments, which are a direct result of being exposed to adversity or traumatic experiences. In contrast to the neutral response, AAD introduces new elements (e.g., personal, relationship, and spiritual growth) and characteristics (e.g., becoming more patient, or acquiring new skills) that did not exist before the exposure to adversity. Therefore, unlike resilience, the concept of AAD is characterised by a higher level of adaptation and

functioning that has exceeded or surpassed previous levels of adaptation and functioning prior to adversity.

According to the AAD theory, positive psychological changes and growthful developments are generated or “activated” because the adversity exposes the limits of individuals. That is, when exposed to adversity, an individual’s previous understandings and expectations are challenged and pushed them to their limits, and in some cases beyond their limits. It is the reaching or exceeding of limits that can be experienced as a transformational process, and opens up individuals to new ways of being, thinking, and new opportunities beyond what was previously planned or even imagined. In other words, when the psychological processes are activated, new perceptions emerge of oneself (self-identity), relationships, and one’s meaning and purpose of life (Papadopoulos, 2007).

This third response, AAD, is most relevant to the present study because the research focus is concerned with investigating positive psychological changes and growthful development associated with PD caregiving. To date, there are no published caregiving studies that adopt an AAD theoretical framework. Rather, AAD has been applied to those directly affected (e.g., refugees), rather than those indirectly affected by exposure to adversity.

2.1.3 Post-traumatic growth model. PTG (see Figure 2) is possibly the most well known and most studied growth theory, model, or concept (Joseph, 2011; Zoellner & Maercker, 2006). Tedeschi and Calhoun (1996, 2004) and Calhoun, Cann, & Tedeschi (2010) maintain that PTG happens in the aftermath of a traumatic event. That is, “growth” occurs after an initial traumatic event (e.g., a life-threatening disease diagnosis, or the death of a loved one) as the term “post” in PTG suggests, and echoes the “post” in post-traumatic stress disorder (PTSD).

Figure 2. The model of Post-traumatic growth

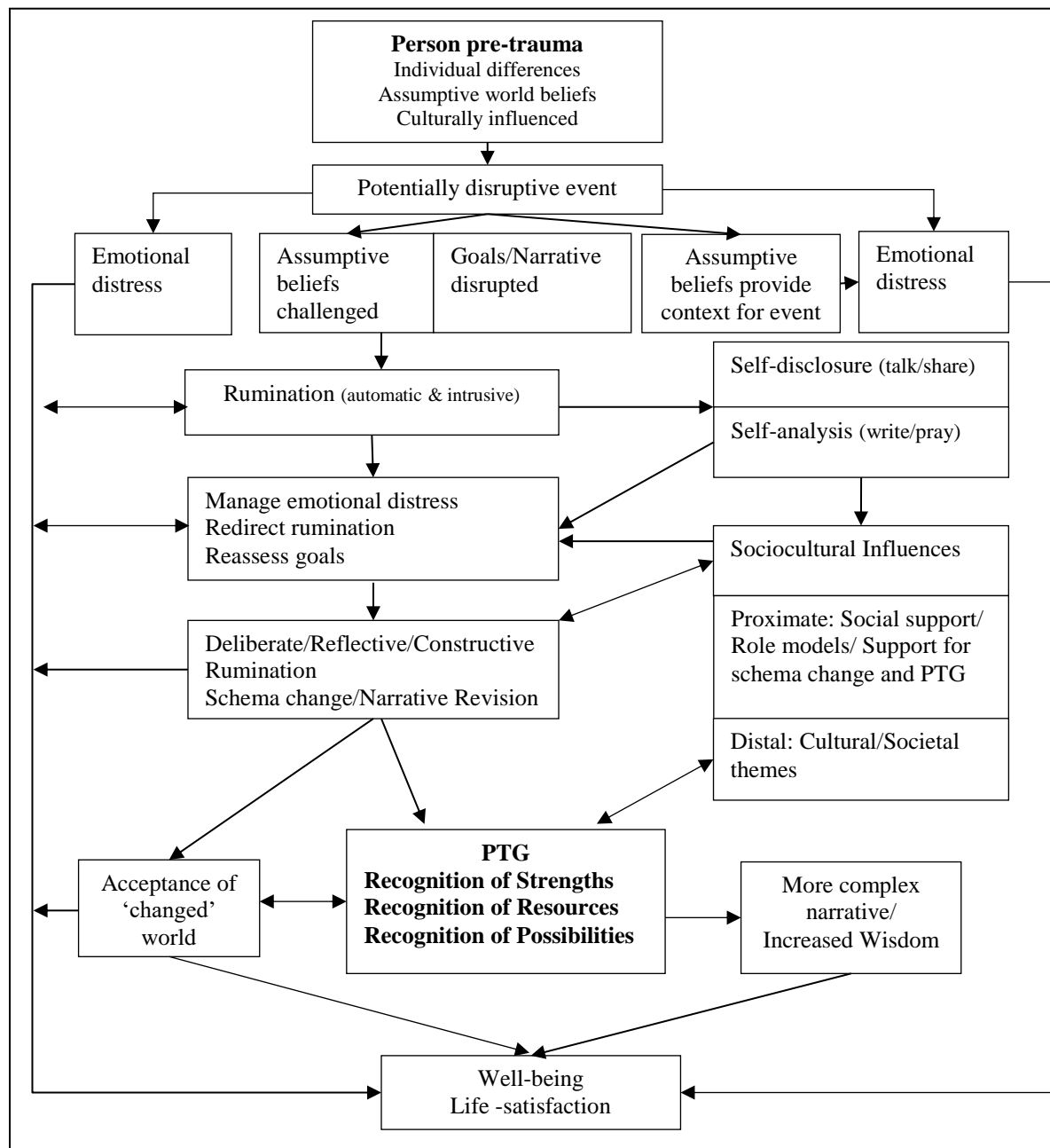


Figure 2. Post-traumatic growth model. Adapted from “The posttraumatic growth model: social cultural considerations” by L. G. Calhoun, A. Cann, and R. G. Tedeschi. In R. Berger & T. Weiss, *Posttraumatic growth and culturally competent practice: lessons learned from around the globe* (pp. 1-14). John Wiley & Sons, Inc.

This model begins with the person pre-trauma and ends with the positive changes and growthful development that can occur from the struggle with life crisis. Like Park (2010),

Tedeschi and Calhoun (2004) and Calhoun, Cann and Tedeschi (2010) emphasise the role of cognitive processing (e.g., deliberate rumination about the event) in an attempt to make sense of it (meaning-making). The recent theoretical model of PTG goes beyond the meaning-making model by emphasising the sociocultural processes and factors that play a role in the possibility of PTG (Calhoun, Cann & Tedeschi, 2010). In contrast to the meaning-making model was limited to the cognitive and emotional processes. This recent model proposes that deliberate rumination, aided by self-disclosure of thoughts and perspectives of the event or experience in a supportive social environment, as well as how others respond to the self-disclosure, play important roles in growth as an outcome. It is through these processes, that individuals receive alternative ways of looking at the situation from others, and this helps to incorporate new perspectives, assumptions, beliefs or schemas as a result of the stressful life event (Calhoun, Cann & Tedeschi, 2010; Tedeschi & Calhoun, 2004).

Tedeschi and Calhoun (2004) identifies five common positive changes post-trauma which include: (1) an increased appreciation of life and a refined sense of priorities; (2) strengthening of relationships; (3) a sense of increased personal strength, such as feeling stronger, more self-assured, and better able to face future challenges; (4) identification of new possibilities or a sense of purpose for one's life; and (5) spiritual development (see Figure A3). However, in the most recent model, these five domains of positive changes have been revised to three dimensions of PTG including (i) recognition of strengths, (ii) recognition of resources and (iii) recognition of possibilities. PTG theory also suggests that PTG mutually interacts with life wisdom and the development of life narrative. These positive changes overlap with the outcomes of meaning-making in the revised meaning making model and growth-ful development in AAD theory. However, the most recent model adds to the understanding of PTG by explicitly acknowledging that cultural influences play a

significant role, either directly or indirectly in shaping assumptive beliefs as well as affecting other elements of the model such as rumination and self-disclosure.

Firstly, *proximate influences* such as people with whom the affected individual interacts with (e.g., friends, family, religious groups) exert influences on the person affected depending on whether they respond positively or negatively to what the individual says or does following the traumatic event. Secondly, *distal cultural influences* such as geographical area, or social media, television and books can also exert an influence on the affected. These cultural influences can shape peoples' worldviews and assumptive beliefs held by individuals, and this in turn can affect aspects of the PTG model, including rumination and self-disclosure and ultimately the possibility of PTG across cultures.

In terms of rumination, differing beliefs across cultures about personal control, sources of causation and stability overtime have been found to play a role in the likelihood of PTG. For example, beliefs about stability over time, individuals whose worldviews anticipate change and more readily accept contradictions may experience less cognitive disruption when a stressful event occurs and in turn, less PTG because the individual believes that whilst things may seem bad after the traumatic event, it does not mean things will stay bad.

In terms of self-disclosure, research has shown that societal norms about disclosing such information can have an influence on self-disclosure and in turn the possibility of PTG. For example, the reluctance to discuss domestic violence because of perceived negative consequences in certain cultures may impede the likelihood of PTG. (Calhoun, Cann & Tedeschi, 2010).

This recent model also makes explicit that some individuals who experience a potentially stressful or traumatic life event will not perceive it to be disruptive to their personal goals, narrative or worldview. Thus will not engage in meaning-making processes

and in turn impedes the possibility of PTG. Nonetheless longitudinal studies have shown that whilst individuals score low on PTG, they report other positive outcomes such as life satisfaction or well-being, as illustrated in Figure 2 (Calhoun, Cann & Tedeschi, 2010).

2.2 Theoretical Conceptualisations Underpinning the Present Study of the Carer Experience and a Comparison of Growth Models Regarding Suitability Representing these Conceptualisations

The previous section served as an overview of each growth theory/model. Each theory or model seeks to explain the same phenomenon of positive psychological changes and growth-ful development in the aftermath of adversity. There is a high degree of consensus amongst these theoretical frameworks, but there are also differences (Park, 2010).

In the growth literature, some conceptualisations are used interchangeably (Blore, 2012), but the present study is based on the assumption that these conceptualisations are not interchangeable. Although the differences between conceptualisations are subtle they actually refer to different entities due to the theorists' differing viewpoints of growth (Blore, 2012). Examples of differences amongst these three theories pertain to, but are not limited to: (a) the way each theory/model conceptualises the foundation of positive psychological changes and growth-ful development, and (b) the way each theory/model conceptualises this phenomenon as an outcome versus coping strategy.

These differences are investigated in regards to how appropriately each growth model matches conceptualisations of the present caregiving experience study, namely: (1) Carers are exposed to adversity, (2) Carers' experience of growth-ful developments are adaptive coping strategies due to exposure to adversity, (3) Seismic experiences shatter the assumptive world to create changes in global meaning, (4) "Is-ought discrepancy" reduction is a process of positive psychological change amongst PD carers, (5) Traumatization is not a necessary

prerequisite for growth-ful development, and (6) The perception of stress is subjective, and (7) The perception of growth is subjective.

2.2.1 Conceptualisation one: Carers are exposed to adversity. The present study conceptualises that those providing care for persons with PD are likely to be exposed to adverse events, situations, and experiences during the PD caregiving journey that may cause a certain amount of psychological discomfort, distress, loss, and pain. This is based on the abundance of evidence that demonstrates the negative effects of PD caregiving in the existing PD caregiving literature. As previously mentioned, it is well recognised in the literature that providing care for persons with PD can be stressful and burdensome, (Caap-Ahlgren & Dehlin, 2002; E. Miller et al., 1996; O'Reilly et al., 1996) and even traumatic (Arber & Venn, 2011; Williamson et al., 2008).

2.2.2 Conceptualisation two: Positive psychological changes and growth-ful developments are both an adaptive coping strategy and an outcome of exposure to adversity. The present study is also based on the premise that the PD caregiving situation also provides an opportunity for positive psychological changes and growth-ful developments. As previously mentioned, Sanders (2005) argues that without first experiencing strains and losses associated with dementia caregiving, gains may not subsequently develop. The revised meaning-making model conceptualises this phenomenon as an adaptive *coping strategy*. In contrast, the majority of influential growth theories (i.e., PTG and AAD) conceptualise the phenomenon of positive psychological changes and growth-ful development in the aftermath of adversity as both a *process* and an *outcome* (or by-product) of the struggle with a traumatic event. Recent PTG longitudinal studies focused on survivors of breast cancer (Danhauer et al., 2015; Saccinto, Prati, Pietrantonio, & Pérez-Testor, 2012; Seligman, 2011) and their loved ones (Moore et al., 2011) that show changes in PTG over time. For some cancer survivors, they reported a modest yet significant increase,

others reported an impressive increase and for some PTG scores remained stable over an 18-month period (Danhauer et al., 2015). Considering these findings as well as propositions of the PTG theoretical framework, the present study adopts the theoretical viewpoint that self-perceived positive psychological change and growth-ful development are both an adaptive coping strategy and an outcome of exposure to adversity, depending on the moment in time and healing.

2.2.3 Conceptualisation three: Seismic experiences shatter the assumptive world to create changes in global meaning. Consistent with the revised meaning-making model (Park, 2010), the present study is based on the conceptualisation that everyday tasks and experiences associated with PD caregiving could potentially be considered seismic enough to shatter the assumptive world (or global sense of meaning) of the loved ones providing care (i.e., their goals, beliefs, and subjective sense of meaning). It is assumed that the shattering of the assumptive world leads to emotional distress, which in turn activates the process of rumination to make-sense of the experience, and ultimately leads to self-perceived positive psychological changes and growth-ful developments.

One example of a potentially seismic event or experience that may occur during the PD caregiving situation is effects of Rapid Eye Movement (REM) sleep behaviour disorder. REM sleep behaviour disorder is a non-motor manifestation of PD (Jankovic, 2008). It is characterised by violent dream content and is typically “accompanied by yelling, swearing, grabbing, punching, kicking, jumping and other dramatic, violent and potentially injurious motor activity” (Jankovic, 2008 p.373). Although it is estimated that REM sleep disorder is prevalent in one-third of persons with PD, the effects are likely to have negative and injurious consequences on the loved ones providing care if they are sharing a bed with their person with PD at the time of an episode (Jankovic, 2008). Hence, this experience in itself can be a seismic event for the loved one providing care.

Post-traumatic growth theory (Tedeschi & Calhoun, 2004; Cann, Calhoun & Tedeschi, 2010) positions the shattering of fundamental assumptions and beliefs as the keystone of its theoretical framework. In contrast, other theorists argue that it is the loss of goals (e.g., Austin & Vancouver, 1996; Dalgleish, 2004; Rasmussen, Wrosch, Scheier, & Carver, 2006), and violation of expectations (e.g., Heine, Proulx, & Vohs, 2006) that are more powerful in generating distress than the violation of beliefs (Park, 2010). Due to the lack of research supporting one meaning-making process of change over the other in regards to PD (whether it is the shattering of beliefs or violation of expectations and loss of goals that initiates meaning-making processes for positive change and growthful development), this study adopts the shattering of global meaning because it is all encompassing, allowing for a greater range of information without favouring one paradigm over another.

2.2.4 Conceptualisation four: “Is-ought discrepancy” reduction is a process of positive psychological change. The “is-ought” discrepancy is referred to as discrepancy between what *is*, or a caregiver’s appraisal of their reality (actual), versus their appraisal or beliefs about how life *ought* to be (Leipold et al., 2008). For example, the belief that a “loved one is for life,” in other words getting married and living a long and happy life with a spouse, versus having a spouse diagnosed with a life-limiting disease, which has the potential to negatively impact the quality and duration of time together. This study is based on the assumption that positive meaning-making processes serve to reduce the “is-ought” discrepancy, ultimately alleviating distress, as well as the profound sense of loss and suffering that may accompany the caregiving situation.

2.2.5 Conceptualisation five: Traumatization is not a necessary precursor for growthful development. The present study is also based on the premise that for a loved one providing care to report self-perceived positive psychological changes and growthful development, they must perceive the PD caregiving situations as stressful but not necessarily

traumatic. Notwithstanding, it is acknowledged that the PD caregiving situation has potential to be extremely stressful, distressing and traumatic for the loved ones providing care. For example, one of the side effects of long-term medication use is *dyskinesia*, which is characterised by involuntary uncontrollable movement resulting from an excessive amount of dopamine (Foltynie & Kahan, 2013). In this state, the person with PD will appear to thrash around, which can be very distressing and traumatic not only for the person with PD (to lose control of their own body), but also for witnesses (Frazier, 2000) including loved ones providing care. Other possible examples of seismic events or experiences are visual and auditory hallucinations that can be experienced by persons with PD. Visual and auditory hallucinations that can be extremely frightening for the loved ones to observe in their persons with PD, in conjunction with loss of function and increased dysfunction compared to the persons with PD's pre-PD functioning. It is one thing to live with someone who has always had these experiences, but it is another to watch them deteriorate until they become a shell of their previous selves.

However, whilst it is recognised that the caregiving experience has potential to be traumatic for the loved ones providing care, this study is not based on the premise that the loved one providing care has to be traumatised to go on to report positive psychological changes and growthful development. It is based on this assumption that makes the AAD a more suitable framework to study PD caregiving. Papadopoulos (2007) who developed the AAD theory argues that firstly, PTG theory (Tedeschi & Calhoun, 2004) is based on the assumption that for "growth" to occur an individual must be traumatised, and secondly, "growth" occurs after an initial traumatic event. However, Papadopoulos is not correct in this assertion about the conceptualisation of PTG. However, closer examination of the theoretical model of PTG indicates that theorists (Tedeschi & Calhoun, 2004; Calhoun, Cann, and Tedeschi 2010) do not propose that that an individual must be traumatised to go on to

experience PTG, rather it is the shattering of the assumptive world. Nevertheless, to avoid any miscommunications in this study, AAD theory is favoured because firstly it does not make mention of trauma, in the name or the conceptualisation (unlike PTG), and secondly it does not assume that people have been traumatised, and instead it proposes positive psychological changes and growthful development can occur during persisting *exposure to adversity*, throughout the caregiving situation (Papadopoulos, 2007). Considering the ongoing, progressive course of PD, it appears more adept to assume loved ones providing care for persons with PD undergo persisting exposure to adversity, rather than necessarily reacting to an initial traumatising. Although news of initial diagnosis may be traumatising, it does not have to be trauma to elicit a positive or growthful experience. This conceptualisation is also in line with the revised meaning-making model that postulates a stressful experience or event as the foundation of positive psychological change, and assumes that causative trauma does not necessarily determine an individual's ability to experience positive change.

2.2.6 Conceptualisation six: The perception of stress is subjective. Consistent with the theoretical viewpoints of the AAD theory (Papadopoulos, 2007), the PTG theory (Tedeschi & Calhoun, 2004) and the revised meaningmodel (Park, 2010), this study does not assume that events (such as the PD diagnosis), and caregiving tasks and experiences (such as attempting to provide care to a person with PD who is experiencing a psychotic episode), on their own are stressful or traumatic for all loved ones providing care for persons with PD. Instead, it is the caregiver's initial appraisal or perception of the event, caregiving task or experience as being stressful or traumatic, rather than the event, caregiving task or situation in itself. Consequently, this study is based on the conceptualisation that some events and caregiving tasks and experiences are perceived as stressful or traumatic by some loved ones providing care, but not by all.

2.2.7 Conceptualisation seven: The perception of growth is subjective. A minority of growth theorists including Park (2010) and a few others (see Affleck & Tennen 2002; Filipp, 2001) argue that veridical (objective, real or actual) growth is rare, and non-veridical (subjective perception or impression) growth is most common. Whereas AAD and PTG models conceptualise positive life changes as veridical (objective or actual). The revised meaning-making model conceptualises growth as a way of coping to alleviate distress associated with the adversity (Park, 2009). Growth is a result of inaccuracy in perceptions such as positive illusions, wishful thinking, and cognitive bias (Park, 2009). The perception of growth is a defensive, self-protective manoeuvre, because people are motivated to experience or claim personal progress to maintain positive self-regard, as well as positive beliefs about the self and the world (e.g., Affleck & Tennen, 1996; Filipp, 2001; Park, 2010).

This idea is supported by several studies in the growth-literature that have shown that people have a tendency to over-estimate positive change because they are motivated by the psychological existential needs for self-enhancement and self-esteem (e.g., Grawe, 2007; McFarland & Alvaro, 2000; Wilson & Ross, 2001). For example, McFarland and Alvaro (2000) conducted a study whereby participants were randomly assigned to two groups. Participants in the first group were asked to focus on a traumatic event, and the second group were asked to focus on a mildly negative event prior to rating their degree of self-improvement on a series of self-attributes (e.g., compassionate, wise, strong sense of inner strength). Participants in both groups were asked to recall their present level and their past level (pre-event) of self-attributes. Results showed that the trauma group recalled heightened perceptions of self-improvement by deprecating the attributes they had possessed in the past. However, in the present study, it is argued that whether growth is considered veridical or non-veridical is not important. Rather what is imperative is whether growth is perceived in

the eye of the beholder. That is the perception of growth is subjective, and it is true to the person who perceives he or she has grown.

2.3 Chapter Summary

The revised meaning-making model (Park, 2010), the adversity-activation development theory (Papadopoulos, 2007) and the post-traumatic growth theory (Cann, Calhoun, & Tedeschi, 2010) inform the present study. The present study is based on the following conceptualisations. First, is the premise that PD caregiving has potential to be stressful, burdensome and even traumatic for the loved ones providing care for persons with PD. Second, is the premise that PD caregiving has potential for positive psychological changes and growth-ful development, which can be both an adaptive coping strategy and an outcome of exposure to stressor(s). Third, consistent with the revised meaning-making model, in the present study it is assumed that the PD caregiving experience must be perceived by the PD caregivers as sufficiently threatening to the order of their life to activate meaning-making processes necessary for positive psychological change and growth-ful development. Through the shattering of global meaning, rather than just a shattering of beliefs or assumptions (as in the PTG theory). Fourth, it is assumed that the process by which positive psychological changes and growth-ful development occurs are via the “is-ought” discrepancy reduction process. That is, when there is a perceived discrepancy between what *is* and about how things *ought* to be, this activates meaning-making coping processes that result in perceived positive psychological change and growth-ful development.

Fifth, in the present study, it is not based on the premise that the loved one providing care for persons with PD must be traumatised, neither is it assumed that positive psychological changes and growth-ful development occurs after an initial traumatic event. Rather, the foundation of positive psychological changes and growth-ful development is the

persisting *exposure to adversity* throughout the caregiving situation. Hence, the AAD conceptual foundations make AAD a more suitable framework to study PD caregiving.

Finally, consistent with all influential growth theories/models, in the present study it is assumed that the foundation for positive psychological changes and growth-ful development is the PD caregiver's perception of the PD caregiving situation being stressful as opposed to the PD caregiving situation itself. Furthermore, Park (2010) argues that people are motivated to claim personal progress in order to maintain positive self-regard, as well as positive beliefs about the self and the world. Hence Park (2010) postulates that positive psychological change and growth-ful development is non-veridical. In contrast PTG and AAD theorists consider it to be veridical. In this study it is argued that what is most relevant is not whether growth is veridical or non-veridical. Rather what is most valid is the person's own perception/belief that he or she has grown.

This chapter detailed the theoretical conceptualisations underpinning the present study. The following chapter contains the literature review followed by the present study's research assumptions.

Chapter Three: Literature Review

As previously mentioned in the Introductory Chapter, PD caregiving research has focused predominantly on the negative experiences of PD caregiving. A search of 25 psychology databases that included PsychINFO, PsycARTICLES, and the web of science core collection, using the following search terms: “positive experiences [associated with] Parkinson’s disease caregiving,” “positive effects of PD caregiving,” “positive aspects of Parkinson’s disease caregiving,” and “personal growth [and] Parkinson’s disease caregiving” revealed no studies that specifically focused on positive psychological changes and/or growth-ful development associated with PD caregiving.

Given the absence of research dedicated to the positive experience of PD caregiving, a wider search of the caregiving literature was performed. This search revealed a number of qualitative studies (e.g., Netto et al., 2009; Peacock et al., 2010; Sanders, 2005), which have explored positive psychological changes and growth-ful developments in dementia caregiving. In addition, a number of other studies were identified that used quantitative or mixed-method designs to investigate positive psychological changes and growth-ful development in the loved ones of cancer survivors and bereaved caregivers. This chapter, therefore, will present a review of the PD literature, which has identified that PD caregiving can have positive impacts upon loved ones providing care for persons with PD. Furthermore, this chapter will review those caregiving studies in other health areas that have focused on positive psychological change and growth-ful development, before making concluding comments.

3.1 Positive Experiences and Growth-ful Development in PD Caregiving

Examination of the wider PD caregiving literature revealed a small number of qualitative and mixed-method PD caregiving studies that have investigated the PD caregiving experience as a lived experience. Whilst these studies have predominantly examined

caregiving as a negative experience, they have found that caregivers do report some positive experiences associated with PD caregiving (Blanchard et al., 2009; Chiong-Rivero et al., 2011; Habermann et al., 2013; Hodgson et al., 2004; Tan et al., 2012; Williamson et al., 2008). Whilst this is encouraging, these authors recognised that the positive effects of caregiving had not been sufficiently explored in their studies because of the primary focus on the negative effects of caregiving (Blanchard et al., 2009; Roland et al., 2010; Williamson et al., 2008). These authors argue that further qualitative research is needed to better understand this less-explored phenomenon. The studies Blanchard et al., (2009), Chiong-Rivero et al., (2011), Habermann et al., (2013), Hodgson et al., (2004), and Tan et al., (2012) identified some positive aspects of PD caregiving through a primary focus on the negative aspects of PD caregiving, and will now be reviewed.

Chiong-Rivero et al. (2011) examined the impacts of PD primarily from the person with PD's perspective, using what could be broadly considered as naturalistic inquiry (Lincoln & Guba, 1985). Data was collected from eight focus groups. Five groups comprised persons with PD and the remaining three groups comprised loved ones providing care, of which eight were spouses, two adult-children, and five other relatives. The focus group interview consisted of open-ended questions based on a review of the literature as well as input from several clinicians working with persons with PD. Six general topics were explored during the focus groups interviews and these pertained to the negative effects of PD on physical functioning, emotional status, and social and role functioning, as well as the stigma of PD and fears about the future. In addition, participants were asked one question about the benefits or positive impacts of PD.

The data was analysed using thematic analysis according to guidelines outlined by Ryan and Bernard (2003). The analysis generated seven overarching themes that were identical to the interview questions, which reflects the deductive approach to analysis that the

authors adopted. With respect to the benefits of having PD, some of the persons with PD described positive changes in their life philosophy, such as developing a more leisurely appreciation for life. For example, one person with PD thought that this positive change was due to the physical limitations and restrictions of the disease. The slowed movement imposed by PD had forced him to appreciate that life is a journey to be enjoyed, as opposed to a race. Moreover, there were a number of persons with PD and loved ones who reported that the PD experience had not only strengthened, but deepened their relationship with each other, as well as their relationships with other family members.

Whilst the findings related to these positive aspects of living with PD is encouraging, this study focused largely on the person with PD's experience rather than the experience of the loved ones providing care. The loved ones providing care in this study were only asked to partake in the study on behalf of their person with PD who was in the advanced stages of PD. These loved ones providing care were asked to discuss their perspectives about the impacts of the disease on their persons with PD, rather than describing their own personal experience as a caregiver, and the impacts of PD on them. However, one caregiver stated that she had personally grown stronger and felt closer to her husband (person with PD) and her family since the presence of PD in their lives. These findings suggest that the impacts of PD on both persons with PD and the loved ones providing care may not be entirely negative. What is most relevant to the present study is the possibility that loved ones may also perceive that there may be personal and/or relationship growth as a result of providing care for persons with PD.

In the Chiong-Rivero et al. (2011) study, it appears that the themes were identified in a deductive or top-down way, which is analyst or researcher driven. This approach is in contrast to an inductive or bottom-up approach, which is data-driven. When themes are identified inductively, the analysis is strongly linked to the data and may bear a diminutive

relation to the specific questions that were asked of the participants. Inductive analysis involves “a process of coding the data without trying to fit” the data “into a pre-existing coding frame or the researcher’s analytic preconceptions” (Braun & Clarke, 2006, p. 83). Braun and Clarke (2006) argue that a deductive approach provides not as much of a “rich description of the data, and a more detailed analysis of some aspect of the data” (p. 84). Braun and Clarke also caution that the deductive approach increases the likelihood of the researcher analysing data based on their interests, and fitting the data to the research question. Hence, there is a danger of missing themes that are meaningful to the participant. Based on this argument, the research by Chiong-Rivero et al. may have missed information that was most meaningful to the participants. Given there were six questions relating to negative impacts of PD, and only one on the positive impacts, this may have restricted opportunities for respondents to discuss the positive impacts. The positive impacts indeed may have been more meaningful or important to the caregivers’ experience.

One PD caregiving study has focused solely on the loved ones providing care for persons with PD (Tan et al., 2012). This study was interested more in the negative aspects of caregiving than positive, and aimed to examine coping, adaption, and general well-being in PD caregivers by utilising a “mixed-method, sequential explanatory” design (p. 2235). The qualitative element of the study involved 21 semi-structured interviews with a sample of Singaporean PD caregivers. The majority of the sample consisted of women with two-thirds of the sample being spouses, and the remaining being adult-children, and two friends.

The qualitative data was analysed according to Ritchie and Spencer’s (1994) “Framework” method of qualitative analysis. This method is a type of thematic analysis and is a systematic approach that involves seven key stages: (1) familiarisation [with data], (2) identification of a thematic framework, (3) application of the thematic framework, (4)

indexing, (5) charting, (6) mapping, and (7) interpretation (Gale, Heath, Cameron, Rashid, & Redwood, 2013).

Four themes and eleven sub-themes emerged from the data and pertained to: (1) coping and adaptation, (2) challenges of caregivers, (3) effects of caregiving on the caregivers, and (4) the need for better caregiver support (Tan et al., 2012). Despite this negative focus, the third theme, being effects of caregiving on caregivers was divided into two sub-themes. Firstly, the positive emotional responses, and secondly, the negative effects as a result of caregiving. It was reported that 17 caregivers identified some positive emotional response related to caregiving and that involved: becoming better at relaxing, improved time-management, improved family bonds, and an increased sense of life satisfaction as a result of caregiving. Thus similar to Chiong-Rivero et al., (2011), this finding suggests that the PD caregiving experience may not be entirely negative for loved ones providing care for persons with PD.

Whilst this positive effects finding is again encouraging, the majority of participants were Chinese, therefore social desirability responding may have influenced the positive psychological changes and growth-ful development. In Asian cultures, providing care for a family member, especially an older relative, is highly valued as a moral obligation, and can be considered one of the purest manifestations of the values of *familism* and filial piety (Marquez-Gonzalez, Romero-Moreno, & Losada, 2010; Parveen & Morrison, 2012; Parveen, Morrison, & Robinson, 2011). “Familism, defined as “strong feelings of loyalty, reciprocity, and solidarity among family members” (Ramos, 2004), is considered the root of caregiving” (Parveen & Morrison, 2012, p. 713). In other words, one may be considered a good person if he or she provides care for relatives because cultural and religious beliefs dictate that the caregiving role should be fulfilled with patience, satisfaction, dignity and even joy (Pachana, Laidlaw, & Knight, 2010; Parveen et al., 2011). Further, Parveen and Morrison (2012) found

that South-Asian caregivers reported significantly more benefits and gains associated with caregiving than British caregivers. Given this, the Chinese loved ones providing care in the Tan et al. (2012) study may have been reluctant to disclose perceived negative aspects of caring for an elder, for fear of being judged negatively if they reported feelings of anger, resentment, inundation, or burden associated with caregiving in an Asian society.

Therefore, the finding in the Tan et al. (2012) study pertaining to growth-ful development reporting may be more reflective of social desirability, and/or due to the collectivist cultural values relating to the care of family, rather than the possibility that PD caregiving can in fact be a positive and growth-ful experience. It may also be that Chinese cultural values associated with caregiving pre-dispose carers to experiencing more positive growth and growth-ful experience. Thus, these findings may not easily generalise to an Australian PD caregiving sample and further research on an Australian population is warranted to see if such findings are a cultural phenomenon, or whether there is potential for positive aspects and growth-ful development in PD caregivers irrespective of cultural background.

The Framework method of analysis used by Tan et al. (2012) is also potentially problematic. To reiterate, the Framework adopts a systematic or “spreadsheet” approach (Gale et al., 2013, p.1472) to data analysis and appears to be more aligned with the scientific/objectivistic or positivist/post-positivist research paradigm. Gale et al. (2013) caution that a common pitfall of this spreadsheet approach is that it increases the temptation to quantify qualitative data. That is, themes are identified based on the frequency of occurrence, and the prevalence of themes is assumed to represent importance, significance, meaning, or relevance to participants. Holliday (2007) contends that this kind of quantification is often meaningless, and asserts that, just because certain words, themes or categories occur more frequently in the speech of one participant, or group of participants,

this does not mean they are the most important or meaningful to the phenomenon under-investigation. Rather, it has been argued that the high frequency of occurrence may be better accounted for by other reasons or factors, such as a greater willingness or ability to talk at length about the topic (Holliday, 2007; Vaismoradi, Turunen, & Bondas, 2013).

It appears that Tan et al. (2012) did quantify the qualitative data because themes were presented numerically, such as 17 caregivers reported positive effects of caregiving. This has implications for the findings, because it appears that themes were identified based on frequency of occurrence. However, there may have been other mentions (albeit infrequent) of positive experiences, but because they were scarce they were not considered important by the researcher. Therefore the researcher may not have identified infrequent reference as a theme or sub-theme. This may have resulted in skewed or misrepresented data conclusions because the positive experiences were not represented adequately due to research methods, thus positive experiences overlooked.

Furthermore, although it is proposed that this Framework method allows for within and between case analysis, it appears that in this application, the analysis was orientated more towards the general rather than the specific individual. That is, the focus was more nomothetic rather than idiographic, and thus this does not easily capture the lived experience of the PD caregiver. Given that PD is a unique disease that affects every person with PD differently, it can in turn affect the loved ones differently. Therefore the Tan et al. (2012) results are not sufficient in elucidating the individual carer's response to the carer's role.

In researching the impacts of PD on loved ones, a methodology that captures the individual differences of this population is required. IPA has an idiographic sensibility (Finlay, 2011) because it seeks idiographic accounts of participants' views and perceptions of the phenomenon under-investigation and examines how participants make sense of their lived experience. Researchers using an IPA approach gather accounts from multiple

participants' perspectives, and subsequently proposes a general broad description of the phenomenon under-investigation (Smith & Eatough, 2012).

Hodgson, Garcia and Tyndall (2004) used an IPA approach to study the lived experience of couples living with PD, from the collective perspective of both the person with PD and their spouse (who was also the primary caregiver). Hodgson et al. argued that previous PD caregiving studies "have used intensive interviews designed to examine the patient's perspective" of the impacts of PD, whereas Hodgson et al. was particularly interested in the negative impacts of PD on couples (p. 114).

Hodgson et al (2004) conducted interviews with the couples. Data was analysed according to the Colaizzi (1978) phenomenological data analysis method. Analysis revealed five thematic clusters which indicated that the couples perceived that the presence of PD had been both a "strain" and a "blessing" on their relationship (p. 107).

In terms of the gain-related findings, some of the participants reported that dealing with the challenges imposed by PD had brought them closer together as well as affirming their commitment to one another. In a few cases, participants reported that PD had saved their relationship. For example, one of the spouses reported that she believed that PD had changed her husband (person with PD) for the better, and described him as a nicer person who had been more concerned about his family since he was diagnosed with PD.

Like the previous studies reviewed, these gain-related findings indicate that the PD caregiving experience may not solely be negative. Nevertheless, there are limitations in terms of the data collection method used in the Hodgson et al. (2004) study. The couples were interviewed together, rather than separately, as it was argued that interviewing the couples together allowed for a "rich landscape of each couple's relationship in full detail" (p.103). However, interviewing both the person with PD and their spouse together may limit self-disclosure. For example, the spouses especially may not have felt they could speak

freely about the negative personal and relational impacts of PD, for the fear of upsetting their loved one with PD.

Babcock, Gottman, Ryan, and Gottman (2013) maintain that when working with couples in the context of marital counselling, each couple in the first instance needs to be interviewed together, and subsequently each person needs to be interviewed separately in order to permit each party to speak more freely. This assessment and intervention model is designed for gaining more accurate and broad information about each person's perceptions of the quality of his or her relationship. Thus, in the Hodgson et al. (2004) study, those spouses who reported positive effects on their relationship, may have felt pressure to do so in an attempt to protect their person with PD, and keep hidden or down play the personal negative impacts of caregiving for fear of upsetting their person with PD. This could have implications on study findings as loved ones may have been overstating the positive experiences associated with PD caregiving.

Nonetheless, the IPA approach used in the Hodgson et al. study had methodological strengths. Data was analysed at a latent or interpretative level, which is in contrast to analysing data at a semantic or explicit level. At a semantic or explicit level, themes were "identified within the explicit or surface meanings of the data, and the analyst is not looking for anything beyond what a participant has said or written" (Braun & Clarke, 2006, p. 84). At a latent level, however, themes are identified through interpretation. This is when analysis goes "beyond the semantic content of the data", and the analytic process progressed "from description, where the data has simply been organised to show patterns in semantic content and summarised" to a deeper level of interpretation. At this level, the researcher uses psychological theory and knowledge "in an attempt to theorise the significance of the patterns and their broader meanings and implications" (Braun & Clarke, 2006, p. 84).

Therefore, by utilising an IPA approach, Hodgson et al. (2004) went beyond producing a description of the PD experience from the perspective of PD patients such as that produced by Chiong-Rivero et al. (2011) or Singapore PD caregivers as produced by Tan et al. (2012). Hodgson et al. (2004) utilised their own personal knowledge and experience working with the elderly and more specifically persons with PD, combined with psychological theory – the biopsychosocial model of chronic illness – in order to make psychological sense of the data. This, in turn, permitted a greater in-depth understanding of the actual everyday lived experience of couples living with PD. This is in contrast to the Tan et al. (2012) and Chiong-Rivero et al. (2011) studies whereby interpretation was absent or lacking. That is, themes were identified at a semantic or surface level rather than a latent or interpretative level, where interpretation goes beyond the surface of what participants say.

Whilst the Hodgson et al. (2004) findings provide a better and more in-depth understanding of what it is like for a couple to live with PD, these findings did not provide an understanding of what it is like solely from the carer or spouse's perspective. As previously mentioned, some positives were expressed by the spouses/carers. However, the attributes of these spouses were not categorised or further investigated.

One PD caregiving study (Blanchard et al., 2009) adopted an IPA approach to focus on the adult-children's experiences of having a parent with PD. Data was collected using semi-structured interviews, and were transcribed and analysed according to the Colaizzi (1978) phenomenological data analysis method. Seven thematic clusters were identified and one of the clusters pertained to the positive influence of PD on their lives, such as developing a more positive outlook on life in the wake of the PD diagnosis, which included a greater perceived ability to find the positive in the negative circumstances. Several adult-children in this study perceived that the presence of PD had not only improved their relationship with their parent with PD, but also improved family bonds with their own spouse or partner and/or

siblings. In addition, some adult-children providing care for a parent with PD reported observing positive changes in the relationships between their own children and the children's grandparents (where one of the grandparents had PD), which they attributed to the presence of PD in the family unit (Blanchard et al., 2009).

While many of the adult-children in this study described caregiving as part of their experience, none were identified as being the primary caregiver of the parent with PD. Rather, their non-PD parent was identified as the primary caregiver, and these adult-children participants were providing supplementary caregiving to the non-PD parent. These findings indicate that there is potential for the supplementary caregiver to experience relationship growth. However, because of this supplementary role, it is unclear if the participants were in fact the primary caregiver, and if they would also experience positive and growth-ful experiences associated with PD caregiving. It is unclear if the positive and growth-ful experiences are because of the supplementary nature of the caregiving role rather than the caregiving role per se.

One recent study focused on adult-children who were the primary caregivers for a parent with either Alzheimer's disease (AD) or PD (Habermann et al., 2013). This study comes from a larger mixed-method, longitudinal, randomised clinical trial, which aimed to investigate coping strategies employed by primary caregivers with the overarching aim to improve caregiving skills in these two disease populations.

The qualitative component of this study involved in-depth semi-structured interviews with these caregivers. The original study's aim was not to investigate the positive aspects or satisfying caregiver experiences for these two diseases. Nonetheless, Habermann et al. (2013) made a conscious decision to include positive experience questions because these authors recognised the shift away from solely studying caregiving burden and the negative aspects of caregiving (in other health conditions such as dementia). Habermann et al.

thought a shift was needed in PD caregiving research, to more completely and holistically study the PD caregiving experience.

Data was analysed using “a qualitative descriptive approach” as defined by (Sandelowski, 2000), and a *conventional content analysis* as per Hsieh and Shannon (2005) recommendations. Conventional content analysis is a type of content analysis that typically adopts an inductive approach to analysis. Both of these approaches seek to describe the phenomenon from the perception of the persons who are living it (Vaismoradi et al., 2013).

In this study, the data was analysed at a semantic or explicit level. Data analysis identified three themes that pertained to relationship growth: (1) spending and enjoying time together, (2) appreciating each other and becoming closer, and (3) returning or giving back care to their parent. Here, caregiving was positively reframed as an opportunity to give back to their parent (having been brought up and cared for by their parent), which brought about a sense of joy. Whilst not every participant identified a positive experience, Habermann et al. (2013) concluded that caregivers who reported positive experiences expressed fewer feelings of being overwhelmed or distressed by their situations. These findings pertaining to positive relationship growth are again encouraging; but, because the responses from both PD and AD caregivers were combined, it is unclear if these positive experiences related to just AD caregiving or whether the findings pertain to both AD and PD caregiving. Thus it is unclear if relationship growth for primary caregivers of persons with PD is possible.

Furthermore, in both the Blanchard et al. (2009) and Habermann et al. (2013) studies, the samples were limited to adult-parent relationships. These positive findings may be reflective of that particular family relationship dynamic rather than the caregiver role per se. Providing care for a parent with PD has been found to be different to providing care for a spouse with PD with spousal caregivers’ perceiving the PD caregiving situation as more stressful and burdensome than adult-children caregivers (Aarsland et al., 1999; Caap-Ahlgren

& Dehlin, 2002; Carter et al., 2010). It has been argued that spousal PD caregivers report more burden because they spend more time with their person with PD and are more emotionally connected to the person with PD than adult-children who provide care for a parent with PD (Shin, Lee, Youn, Kim, & Cho, 2012). Hence, providing care for a parent with PD may be a different experience and thus may take on a different meaning and present different challenges, as well as different growth opportunities, compared to PD spousal caregiving.

There are strengths to the Habermann et al. (2013) study. Firstly, authors moved away from the traditional focus of studying solely the negative aspects of PD and AD caregiving. Secondly, in terms of the methodological approach, an advantage of the conventional analysis approach compared to the content analysis approach is gaining information for study participants without imposing preconceived categories or theoretical perspectives on the data (Vaismoradi et al., 2013). Because it's inductive in its approach to the analysis, findings are based on participants' unique perspectives and are grounded in the data (Vaismoradi et al., 2013) much like the previously mentioned IPA studies.

Nonetheless, conventional content analysis is not without its methodological limitations (Vaismoradi et al., 2013) given data was analysed at a semantic or explicit level, as opposed to a latent or interpretative level. As previously argued, when discussing the differences between explicit and latent levels of analysis, it could be contended that these approaches produce findings that are limited to the description of what the participants have said during the interview. This type of analysis has been criticised for being a superficial level of analysis (Holliday, 2007), and does not allow the researcher to progress beyond the description of what the participant says to look for meaning and understanding (Braun & Clarke, 2006; Smith & Eatough, 2012; Vaismoradi et al., 2013). The descriptive qualitative approach and the conventional content analysis approach share similar initial analytical steps

to an IPA approach. But the entire analytic steps involved in the descriptive qualitative approach and the conventional content analysis are identical to the initial analytic steps of IPA (Vaismoradi et al., 2013). IPA, however, takes the analytic process a step further by progressing from a descriptive level of analysis to more of a latent or deeper level of analysis or interpretation utilising psychological theory (Vaismoradi et al., 2013).

In sum, these aforementioned PD caregiving studies indicate that both supplementary and primary caregivers, be these adult-children, spouses or family members, can experience positive psychological change and growth-ful development as a result of the caregiving experience. While these findings demonstrate that the lived caregiving experience is not overwhelmingly negative for all PD caregivers, there remains a lack of PD caregiving research that primarily adopts a strength-based approach to investigate PD caregiving. This is not to say that caregiving in other health populations has not been examined from a strengths perspective, and a brief overview of this research will now follow.

3.2 Positives Experiences and Growth-ful Developments in Dementia Caregiving

A search of the previously mentioned psychology databases, using the following term “Positive experiences [associated with] dementia caregiving” identified 183 journal articles, compared to four for “Positive experiences [associated with] Parkinson’s disease caregiving;” “Positive effects of dementia caregiving” identified 44 journal articles, compared to zero for “Positive effects of PD caregiving;” “Positive aspects of dementia caregiving” identified 138 journal articles compared to two when searching the terms “Positive aspects of Parkinson’s disease caregiving;” and “Personal growth [and] dementia caregiving” identified 51 journal articles, compared to one for “Personal growth [and] Parkinson’s disease caregiving.” Whilst dementia is distinctly different from experiences of those suffering PD and PD caregivers (Goldsworthy & Knowles, 2008; Habermann & Davis, 2005) dementia was chosen to be reviewed over other chronic diseases due to the similarities

of the conditions. Both diseases are most likely to occur in individuals over the age of 60 years, and the chances of developing either condition increase with age (Deloitte Access Economics, 2011). Both share some similar symptoms including changed cognitive impairment in memory, judgment, orientation and executive function, as well as personality and mood changes (Habermann & Davis, 2005). In addition, dementia can develop with advanced PD. Persons with PD are five times more likely to develop dementia compared to a normal population (Deloitte Access Economics, 2015). Given the progressive nature of both conditions, each requires informal caregivers (usually the adult child or spouse of the care recipient). Both caregiving populations have to cope with problem behaviours that often arise from the progressive cognitive impairment, such as agitation, physical aggressiveness, and hallucinations (Habermann & Davis, 2005). Moreover, each of these progressive neurodegenerative conditions place a significant level of burden on the caregiver over time, which can lead to mental health problems and declining physical health (Dotchin et al., 2014).

Netto et al. (2009) employed a strength-based perspective to explore the positive aspects and growth-ful development experienced by family caregivers of persons with dementia. This Singapore study adopted a qualitative design guided by a grounded theory approach and involved semi-structured interviews with eight daughters, two sons, one spouse and a niece of the person with dementia. Findings revealed that each participant reported having grown through caregiving. Three growth-related themes were identified from the data including: (1) Personal Growth, which included becoming more patient and understanding, becoming stronger and more knowledgeable, and developing increased self-awareness and skills development; (2) Relationship Growth, which included improved relationships with the person with dementia as well as other family members; and (3) Spiritual Growth, which included deepened relationships with God, a positive change in life

perspective, and attaining a sense of altruism, such as an increased desire to “contribute somewhere” as a result of the caregiving experience. It was concluded that amongst the gain-related themes, personal growth was the most commonly reported theme.

Like the Tan et al. (2012) PD caregiving study, participant caregivers were all Chinese, and the majority were adult-daughters providing care for a parent with dementia. Therefore, findings pertaining to positive psychological changes and growth-ful developments may not be easily generalisable to an Australian caregiving sample. Australian PD caregivers are typically the spouse and less often adult-children, and therefore caregiving for a parent with PD may be qualitatively different to providing care for a spouse. Furthermore, the study occurred within an Asian society, which holds certain beliefs and cultures about caregiving. As previously mentioned, findings pertaining to positive psychological changes and growth-ful development may have been overstated due to social desirability, because these participants may have felt societal and cultural pressure to act (or at least present) accordingly with these social/cultural beliefs.

In addition, theme presentation was based on the most frequently occurring themes and as already stated there may have been other mentions of positive experiences and growth-ful developments that were important and meaningful to these participants, but not identified as a theme in the analysis because they were infrequently mentioned. This may mean that findings pertaining to positive experiences may have been understated in this study.

Similar gain-related themes were found in a larger, more diverse sample of dementia caregivers conducted in the USA (Sanders, 2005). In contrast to Netto et al. (2009), Sanders examined both the strains and gains associated with providing care for family members with dementia. Much of the sample consisted of daughters, and the majority were Caucasian. Participants were asked to respond to a series of open-ended questions in a written

questionnaire. “The questions were designed to elicit responses about the caregivers’ overall caregiving experience, including problems, positive and negative changes that occurred throughout their caregiving duration, and their emotional reactions to their caregiving experience” (Sanders, 2005, p. 62).

The qualitative data was analysed using several strategies based on “a grounded theory approach” (Sanders, 2005, p. 62). Analysis revealed that dementia caregivers reported both strains and gains associated with caregiving. Eighty-one per cent of caregivers reported experiencing gains as well as strains, and 19% reported experiencing only strains. Gain-related themes pertained to: (1) spiritual growth and increased faith, (2) personal growth, and (3) feelings of mastery and accomplishments associated with caregiving. In terms of personal growth, caregivers reported becoming more patient and caring, less self-centred, more sensitive and aware of other people’s problems, more responsible, better at setting boundaries and maintaining life balance, and developing a greater sense of peace and gratitude. Like Netto et al. (2009), Sanders (2005) also found that personal growth was a commonly reported gain-related theme.

However, with regards to the data collection method, the qualitative data was collected in written form at the end of a quantitative questionnaire. There are drawbacks to this method. Firstly, written methods do not allow the research participant to clarify the nature of the questions that are being asked, and secondly, it does not allow for probing or clarification by the interviewer (Smith & Eatough, 2007). Therefore, interesting and important information relevant to the research question may be missed, which limits the depth and meaningful understanding of the phenomenon under-investigation (Smith & Eatough, 2012). The positive and growth-ful experience reported by Sanders (2005) may not have been fully explored using this method of data collection and there may be more gain-related experiences that were not elicited due to the data collection method.

3.3 Positive Experiences and Growth-ful Developments in Loved Ones of Those Affected by Other Health Conditions

In addition to dementia caregiving, positive psychological change and growth-ful development has also been investigated in loved ones of cancer survivors (Manne et al., 2004; Mosher et al., 2006; Weiss, 2004); the loved ones of stroke survivors (Bacon et al., 2009; Hallam & Morris, 2013); bereaved HIV caregivers (see Cadell, 2003, 2007); parents providing care for children with life-limiting illnesses such as cystic fibrosis, neurodegenerative metabolic disease, and cerebral palsy (Cadell et al., 2014); and parents providing care for children undergoing cancer treatment (Teixeira & Pereira, 2013).

Cadell (2003) conducted a cross-sectional study to investigate growth-ful development in a sample of bereaved Canadian HIV caregivers. Cadell used the Post-Traumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996) to assess for positive psychological changes and growth-ful development as a result of the HIV caregiving experience. The PTGI is a 21-item measure of positive changes on five domains that include: (1) new possibilities, (2) relating to others, (3) personal strength, (4) appreciation for life, and (5) spiritual growth (Tedeschi & Calhoun, 1996). Cadell found that bereaved caregivers who scored high on distress scales also scored high on the post-traumatic growth scale, and therefore suggested that the more distressed or traumatised the bereaved caregiver, the more growth he or she experienced.

This finding is consistent with the dementia caregiving studies which found that strains and gains associated with caregiving are distinct, yet are also inter-related and co-exist (Farran et al., 1999; Rapp & Chao, 2000; Sanders, 2005). These findings suggest that the very circumstances and caregiving activities that create strain (e.g., tension, losses, burden, and stress) and generate problems in everyday life for the loved ones providing care may also create moments or enduring periods of gratification. Sanders (2005) suggested that

experiencing strains and losses associated with dementia caregiving, potentially provides caregivers with opportunities for positive transformation and growth-ful development. That is, without first experiencing strain and loss, gains may not subsequently develop, or more aptly, be reported by those providing care for their loved ones.

A cross-sectional study focused on female caregivers providing care for a spouse, parent or child diagnosed with cancer, and found that self-perceived positive changes and growth-ful development was more likely to be reported during moderate times of stress, as opposed to low stress or high stress (Cassidy, 2013). In other words, in an event, situation or environment where perceived stress is either low or extreme, the likelihood of positive psychological changes and growth-ful development diminishes. Thus, it has been argued that an optimum environment is required to bolster positive psychological change and growth-ful development (Cassidy, 2013; Helgeson, Reynolds, & Tomich, 2006; Zoellner & Maercker, 2006).

There are numerous caregiving studies across different populations (e.g., Cadell, 2003, 2007; Cadell et al., 2014; Cassidy, 2013; Hallam & Morris, 2013; Manne et al., 2004; Moore et al., 2011; Mosher et al., 2006; Tedeschi & Calhoun, 2004; Teixeira & Pereira, 2013; Weiss, 2004) that have adopted a quantitative design framework to investigate contextual and personal factors that contribute to positive psychological change and growth-ful development in the caregiving situation. Findings show that several factors are related to positive psychological changes and growth-ful development. These include disease-related factors such as disease severity and disease duration; care-related factors such as frequency and intensity of caregiving tasks, and caregiving duration; caregiver factors such as caregiver demographics (e.g., gender, age, education), personality characteristics (e.g., extraversion and optimism) and personal coping strategies (e.g., cognitive, emotional and behavioural coping strategies); care-recipient related factors such as care-recipient demographics (e.g.,

age, gender, ethnicity, education); and relational factors such as the nature of the relationship with the care-recipient, (e.g., spouse, adult child), the quality of the pre-existing relationship, as well as the perceived social support.

There is a high degree of consensus amongst these studies in terms of factors that predict positive psychological changes and growth-ful development. For example, it was found that higher amount of self-reported cognitive processes (e.g., deliberate rumination) the higher the scores on the PTGI. That is, the more cognitive processes employed by the caregivers in order to make sense of their loved one's illness and to contemplate the changes brought about by the diagnosis/illness, the greater the self-reported positive psychological changes and growth-ful development (Hallam & Morris, 2013; Manne et al., 2004; Tedeschi & Calhoun, 2004; Weiss, 2004).

Until more recently the longitudinal course of PTG was poorly understood. There have been a few studies (see McDonough, Sabiston, & Wrosch, 2014; Silva, Crespo, & Canavarro, 2012) that have investigated PTG in breast cancer survivors for 3 – 6 months and up to one-year post diagnosis and found PTG levels stable over time. However, a longer longitudinal study during the 18 – 24 months' post diagnosis, found PTG continued to rise steadily for 18 months, then plateaued 18 – 24 months' post-diagnosis (see Manne et al., 2004) in both cancer survivors and their loved ones.

A recent longitudinal study investigated the course of PTG over an 18 month period post-diagnosis (Danhauer et al., 2015). Findings revealed six trajectories and individual variability between each trajectory group. Three group-based trajectories were stable and did not change significantly over time (of the three groups there was one group with low PTG scores, one moderate and one high PTG scores); two group-based trajectories (one low and one moderate) increased significantly - yet modestly- over time; and one group-based trajectory increased substantially overtime. There were no decreasing PTG trajectories.

Groups who reported moderate to high levels of PTG were more likely to be women who were non-white, relatively young and had undergone chemotherapy. They had higher baselines of illness intrusiveness, depressive symptomology and more active- adaptive coping than women who reporting low levels of PTG. Conversely the women who reported lowest levels of PTG, were older, reported less financial strain; highest level of social support, lowest levels of illness intrusiveness, depression, and active-adaptive coping strategies; compared to the other trajectory based groups. Danhauer et al., (2015) suggest that this group were not challenged by the cancer and experience and therefore required less coping strategies.

These findings suggest that the coexistence of the greater difficulty and effective coping mechanisms may be important for enhancing higher PTG. In addition, these findings are consistent other longitudinal studies (i.e., Manne et. al. 2004; Moore et al., 2011) that show the course of PTG changes over time. These findings support the theoretical framework of PTG that conceptualises the perception of positive change is a process as well as an outcome (Calhoun, Cann, & Tedeschi, 2010).

However, the majority of the aforementioned studies measured positive psychological changes and growth-ful development using the PTGI. One of the main issues with the PTGI is that it has been criticised for not measuring what it claims to measure (Park, 2009). Park states that respondents are required to engage in five evaluations of their experience: (1) evaluate their current weighting of growth (e.g., closeness to others), (2) recall their previous weighting of growth on the same dimension (prior to the trauma or stressful encounter), (3) compare the current and previous weighting of growth, (4) assess the degree of positive change, and (5) ascertain how much of that positive change can be attributed to the trauma or stressful encounter. Park argues that respondents do not actually make such evaluations, but rather offer global impressions or perceptions of veridical change, and therefore results do

not necessarily indicate actual growth-ful development. In other words, the person perceives that they have grown as a result of a stressful situation. Whilst this may be true from their perspective, they may not have actually changed. It can also be argued that the PTGI only measures what it sets out to measure and therefore may miss novel and meaningful information that is relevant to the phenomenon.

Neuman (2011) contends that studies, which are quantitative in design, reduce individuals to numbers and remove the person from the immediacy of the PD caregiving experience, and subject the loved ones providing care (participants) to objectification. Neuman further argues that objectification is problematic in that it treats people impersonally, removes the subjective experience (relevant to people's lives), and thus does not capture or easily translate to the actual lived experience.

Nonetheless, findings from these quantitative or mixed-method studies are beneficial in many ways. Establishing a better understanding of positive psychological change and growth-ful development predictors can be used to inform clinicians working with caregivers. This may enable clinicians while designing psychosocial interventions aimed at targeting and facilitating positive psychological change and growth-ful development.

The goal of the present study is to explore whether caregivers for persons with PD report positive psychological changes and growth-ful development, and to shed more light on the underlying processes of growth-ful development. To reiterate, the goal of this study is not to confirm what factors predict growth-ful development as a result of PD caregiving, and therefore a quantitative research design will not be adopted. A methodological approach, therefore, is required that is suitable for this study's research focus and aims. This will be discussed in detail in Chapter Four.

3.4 Summary and Implications

Most PD caregiving research to date has focused on the negative aspects of caregiving. There is a small emerging portion of literature acknowledging positive psychological changes (e.g., developing a positive attitude towards life, and a new found appreciation for life), and growth-ful development (e.g., strengthening of relationships with person with PD and family members) associated with PD caregiving (Blanchard et al., 2009; Habermann, 2000; Hodgson et al., 2004). However, samples have typically comprised of adult-children providing care for a parent with PD and AD (Habermann et al., 2013), Asian PD caregivers (Tan et al., 2012), or adult-children providing supplementary care to parents with PD (Blanchard et al., 2009). These findings are promising, but they may not generalise to an Australian PD caregiving population, whereby the primary caregivers are typically the PD sufferers' spouses, and less so adult-children.

In terms of the methodological approaches adopted in these studies, some simply described the subjective experience of PD caregivers (Habermann et al., 2013; Tan et al., 2012), or persons with PD (Chiong-Rivero et al., 2011). Other studies, however, did not just simply describe the phenomenon of PD caregiving, but used IPA's methodological approach to describe the subjective experiences through a deeper cognitive and emotional analysis. In doing so, Hodgson et al. (2004) and Blanchard et al. (2009) utilised personal and psychological knowledge to further capture, illuminate and appreciate the lived experience of the respondents. This extended the analysis beyond description of the phenomenon under-investigation, which in these cases were the impacts of PD on couples (Hodgson et al., 2004) and the impacts of PD on adult-children providing supplementary care to a parent with PD (Blanchard et al., 2009).

Moreover, these studies have given primacy to the negative aspects of PD caregiving (Blanchard et al., 2009; Chiong-Rivero et al., 2011; Habermann et al., 2013; Hodgson et al.,

2004; Tan et al., 2012) and have adopted a deficit-based perspective rather than a strength-based perspective. Whilst gain-related findings were identified in these studies, the researchers recognised the positive aspects of PD caregiving were not sufficiently explored and as such these researchers called for more qualitative research using a strength-based perspective to expand the focus of PD caregiving research to include positive aspects, and to develop an insight into the overall experience of caring for a loved one with PD (Blanchard et al., 2009; Habermann et al., 2013; Williamson et al., 2008). This research, like dementia caregiving research (e.g., Peacock et al., 2010) stand to inform interventions designed to better support family caregivers in their journey and to assist PD caregivers to capitalise on these resources and strengths.

Most of what is known about the positive psychological changes and growth-ful development as a result of caregiving comes from the dementia caregiving research, or cancer survivor caregiving research or bereaved caregivers who provided care for partners and family members with cancer or HIV. Whilst it is acknowledged that the PD caregiving situation differs from these caregiving situations, dementia and PD caregiving are most similar due to the progressive and debilitating nature of both neurological conditions. Collectively, the studies discussed in this chapter emphasise that the path to self-perceived positive psychological changes and growth-ful development is not a simple one and warrants further investigation.

Chapter 4: Research Framework

The purpose of this chapter is to highlight the researcher's assumptions that were brought to this study, and to position these assumptions in relation to: (a) research paradigms in psychology and the PD caregiving research literature, (b) the philosophy that underpins the assumptions, and (c) the chosen methodology. To reiterate, the methodological approach of interpretative phenomenological analysis (IPA) (Smith & Eatough, 2007; 2012) was adopted to address the overarching aims of the study. The overarching aims were to examine and elucidate the lived experience of loved ones providing care for persons with PD. This chapter will argue why IPA was best suited to this study's research focus and broad question. This chapter will also overview IPA and its philosophical underpinnings, before outlining the exemplary methods of both data collection and data analysis for an IPA study.

4.1 Researcher's assumptions underpinning this study

4.1.1 Assumption one. The focus of the present study is concerned with the loved one's subjective experiences of providing care for persons with PD and the meanings they make about the PD caregiving situation, rather than the objective nature of PD caregiving. The first assumption that has been brought to this study is that each loved one can experience the same objective condition(s), such as the time of receiving the PD diagnosis, in substantially different ways. This assumption is more aligned with a *constructivism* paradigm, which is an alternative view to the more traditional *positivism/post-positivism* paradigm that dominates the psychology discipline, as well as much of the PD caregiving research. Positivists/post-positivists ascribe to the notion that everyone experiences the world in the same way and that there is one reality, or truth, that is "real" and "out there" in the world, waiting to be discovered (Willig, 2013).

In contrast, constructivism questions whether people experience social or physical reality in the same way (Willig, 2001). Constructivists ascribe to the notion that there are

multiple realities as several people can see, hear, and even touch the same physical object, yet come away with different meanings or interpretations of the experience of that object (Willig, 2001). This is because constructivists see experience as being mediated by the thoughts and beliefs, expectations and judgements that the individual brings to the experience (Willig & Stainton-Rogers, 2008). Constructivism is based on the notion that people attribute meaning to events, which in turn shape their experiences (Willig, 2001).

4.1.2 Assumption two. The second assumption that has been brought to this study is that the same illness experience can be interpreted to mean considerably different things for different people. This means that each loved one can interpret the PD caregiving experience differently when providing care for a person with PD. Hence, a method of inquiry is needed, which is consistent with these assumptions and that can capture the meanings, context and subjective realities related to the experience of providing care for persons with PD.

4.1.3 Assumption three. The third assumption that has been brought to this study is that the way the loved ones respond to the PD caregiving situation is highly individualised because each human being has their own specific and idiosyncratic way of perceiving, processing, reacting and responding to events that occur within the PD caregiving situation. Hence, a method of inquiry is required to take into account the uniqueness and the complexities associated with the PD caregiving experience and individual differences.

4.1.4 Assumption four. The fourth assumption that has been brought to this study is that the meanings people ascribe to events are the product of interactions with others in their social world (Shinebourne, 2011). This assumption is most aligned with *social-constructivism*, which argues that knowledge is socially constructed. This means that people's interpretations are not idiosyncratic and free-floating, rather they are bound up with social interactions and processes that are shared between other social beings (Willig, 2001).

In the context of this research, participants construct meaning of their experiences and events through the use of language, as they engage in the process of telling their PD caregiving stories. In telling their story, the participant is attempting to make sense of their experiences (or the phenomenon under investigation). The role of the researcher is to then try to make sense of the participant's attempts to make sense of an event or phenomenon. Hence, the present study requires a method of inquiry that allows participants the freedom to tell their PD caregiving story and to share their PD experience in their own personal way.

4.1.5 Assumption five. The fifth assumption of this study is that the participants and the researcher cannot be objectively separated (Shinebourne, 2011). Rather, the researcher and the researched co-create knowledge (Smith et al., 2009). The present study positions the researcher as an active agent in the research, which is in contrast to positivism/post-positivism, where the researcher is positioned as objective, value-free and detached (Willig & Stainton-Rogers, 2008). The participant's role is then one of reporting (typically utilising questionnaires) and the role of the researcher involves examination of the participants. Given that the present study adopts a more social constructivist approach to the topic under investigation, a method of inquiry that allows for exploration of a phenomenon with the loved ones providing care for persons with PD is necessary.

4.1.6 Assumption six. The sixth assumption is that the loved one's descriptive accounts (what they say or write) of their personal PD caregiving experience tells something about their inner private thoughts and feelings, and that these are implicated in the loved ones' experience (Willig & Stainton-Rogers, 2008). However, in this study, the researcher recognises that language (spoken or written) can never simply give expression to experience. Instead, there is meaning in the words that are said or written, as well as what is not said or written. For example, a participant may have difficulty expressing what they are thinking and feeling, or even, a participant may not wish to disclose particular aspects of their inner

private psychological world. Therefore, this study is based on the assumption that in order to make sense or understand (to some degree) the subjective experience of the loved one's experience and inner psychological world, interpretation is required. A methodological approach is required that allows the researcher to interpret the participant's emotional and mental state from what he or she does (or doesn't) disclose. In contrast to methodological approaches that are based on face validity, that is, what the person says is how it is.

In sum, a method of inquiry and a methodological approach is required for this study that: is aligned with the social constructivism paradigm; can capture the positive meanings/sense-making, context, and subjective realities of the loved ones providing care for persons with PD; takes into account the uniqueness and the complexities of the PD caregiving experience; has theoretical commitment to the individual as well as seeking shared experiences and meanings of the loved ones providing care; allows for a non-directive approach to investigation *with*, rather than *of*, the loved ones providing care, allowing them to tell their story in their own way and to capture the sense-making of their lived experience; and finally, the inquiry and approach must also permit interpretation, allowing the researcher to make sense of loved ones positively making sense of their lived caregiving experience.

4.2 Choosing a qualitative methodological approach

In any research project the researcher must choose a methodological approach that is well suited to the project's focus and broad question, the philosophical and theoretical underpinnings (Chapter Two outlines the theoretical assumptions of the present study), as well as being appropriate for the discipline in which the project is being conducted (Vaismoradi et al., 2013). Previous literature has acknowledged that loved ones providing care for persons with PD often feel on the periphery of research endeavours and they do not have a voice or the freedom to share their experiences and needs (Addington-Hall & Ramirez, 2006; Dyck, 2009; McLaughlin et al., 2011). As mentioned in earlier chapters,

there is a predominant use of quantitative inquiry in PD caregiving research. Quantitative inquiry does not lend well to giving voice to participants. The present study chose a qualitative method of inquiry with the view to adopting data collection tools (such as interviews) to allow the participants the freedom to speak about what they perceived was meaningful, and ultimately to give voice to the loved ones providing care for persons with PD.

There are many types of qualitative methods of inquiry, such as (but not limited to) case studies, ethnography, grounded theory, narrative analysis, content analysis, phenomenology, and interpretative-phenomenological approaches. Each has different epistemological and theoretical perspectives, but each “share a similar goal in that they seek to arrive at an understanding of a particular phenomenon from the perspective of those experiencing it” (Vaismoradi et al., 2013, p. 398). “The use of qualitative descriptive approaches such as descriptive phenomenology, content analysis and thematic analysis is suitable for researchers who wish to employ a relatively low level of interpretation, in contrast to grounded theory or interpretative-phenomenological approaches, in which a higher level of interpretive complexity is required” (Vaismoradi et al., 2013, p. 399).

The focus and broad question of the present research project requires a higher level of interpretative complexity, which leads to the use of a qualitative-interpretative paradigm as the methodological approach, and therefore IPA (Smith & Eatough, 2012) was the chosen methodological approach. IPA studies are typically concerned with topic areas that are less-explored; are subjective, humanistic-existential and transformative in nature; and maintain open, flexible, and explorative research aims and questions, as opposed to predetermined hypothesis. Hence, IPA is congruent with the present study’s focus and broad question.

The nature of the present study is indeed existential and transformative because it is based on the notion that humans have capacity to find meaning, and transform adversity into

an opportunity for growth-ful development. The present study is also based on the assumption that humans are meaning-making beings that are driven to understand or make-sense of their experience. IPA is typically used for research studies that are concerned with exploring how people make-sense of critical life events, how people create personal meaning of these junctures, as well as how people make choices in response to these events, and how they relate these experiences or events to their sense of identity (Smith & Eatough, 2012). Therefore, IPA is particularly compatible with the present study's research focus because the overall aim is to explore the positive side of PD caregiving, and to illuminate how the loved ones make sense, ascribe positive meaning, find benefit, and personally transform during the PD caregiving situation.

Moreover, IPA is established as a specifically psychologically-orientated research method (Smith & Eatough, 2012; Willig, 2013) and serves to explore people's psychological and cognitive worlds. Hence, IPA is particularly appropriate for this study because it is concerned with exploring the subjective experience and inner psychological worlds of the loved ones providing care for persons with PD.

Interpretative Phenomenological Analysis also has theoretical commitment to the person not only as a cognitive, but linguistic, affective and physical being. IPA assumes a sequence of connection between people's talk and their thinking and emotional state (Tollefson, 2009; Smith & Osborn, 2008). At the same time, IPA researchers also realise this sequence of connection is not in the least straightforward (Smith & Osborn, 2008).

Consistent with the assumption six, a researcher operating from an IPA approach also acknowledges that people consciously or unconsciously did not always make their inner psychological world (thoughts and feelings) known to outsider. Thus in IPA studies the researcher has to interpret the person's internal psychological world, that is their mental and emotional state from he or she says, and also recognises that any analytic account will be

partial, and the researcher cannot assume that it could ever be the final word on the topic (Smith & Osborn, 2008).

Finally, IPA is recommended for clinical psychology research (Smith & Eatough, 2007, 2012; Story, 2007) and is an appropriate approach for the present study because it is occurring within this discipline. Now that the rationale for choosing IPA as the methodological approach for the present study has briefly been discussed, IPA will be described in detail.

4.3 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis “explores in detail personal lived experience to examine how people are making sense of their personal and social world” (Shinebourne, 2011, p. 44). IPA studies are particularly interested in the “meanings that particular experiences, events and states hold for participants” (Smith & Osborn, 2008, p. 53). A researcher using IPA strives to comprehend “what the world is like from the point-of-view of the participants” (Shinebourne, 2011, p. 44). Researchers operating from an IPA approach engage with participants, typically through interviews, to investigate the individuals’ perceptions of his or her experience, as well as how they are making sense of a particular phenomenon, in order to understand the essential characteristics or the “essence” of the phenomenon under investigation (Merriam, 2002).

Interpretative Phenomenological Analysis places emphasis on “putting oneself [the researcher] in the place of the other [participant] and seeing things from the perspective of another” (Crotty, 1998). Nevertheless, a researcher using IPA acknowledges that it is never completely possible to enter the inner world or reality of the participant without some level of interpretation (Smith & Eatough, 2007; 2012). A researcher using IPA, when interpreting the participants’ experiences, is required to stand back and ask curious and critical questions of the participants’ accounts, with the purpose of gaining a richer analysis, and in turn, a

greater in-depth understanding of the essence of the phenomenon (Smith & Eatough, 2007, 2012; Willig, 2013).

Unlike quantitative methodologies that typically strive to remove the influence of the researcher, IPA emphasises that research is a “dynamic process between both researcher and participant”. It is acknowledged that the researcher “plays an active role in the research process”, and subsequently influences the analysis and study findings (Smith & Eatough, 1996, p.264). The researcher using IPA utilises their own personal and theoretical knowledge to make sense and interpret meaning about what the participant is saying. This results in a more holistic or abstract level of sense-making, and ultimately a deeper and more insightful understanding of the participants’ lived experience (Finlay, 2011; Smith & Eatough, 2007; Willig, 2012), in contrast to descriptive phenomenological research.

4.3.1 Philosophical and theoretical underpinnings of IPA. IPA draws upon the philosophical and theoretical underpinnings of *phenomenology* (Moran, 2002), *hermeneutics* (Palmer, 1969) and *idiography* (Smith, 1995) to inform its distinctive epistemological framework and research methodology (Smith & Eatough, 2007). IPA focuses on an engagement with subjective and personal accounts (Shinebourne, 2011). There is a long intellectual history for each theoretical touchstone; however, it is beyond the scope of the present project to provide a detailed account of the historical background of each. Instead, a brief summary is provided below.

4.3.1.1 Phenomenology. Phenomenology is the study of perception, consciousness, or reality (Willig, 2013). The primary objective of phenomenology is the investigation and description of phenomena as consciously experienced (Spiegelberg, 1975). Phenomenology is a school of philosophical thought that underpins all qualitative research methodologies (Silverman, 2004). The phenomenological research approach differs from the more traditionally or widely used quantitative research methodologies in psychology, as it does not

ascribe to the thought that there is one fixed or completely objective reality. Rather, IPA operates on the premise that there are multiple realities and each individual's reality is shaped by past experiences, existing knowledge, expectations, beliefs or schemas, and culture. Realities are subjective, unique, and forever changing (Smith & Eatough, 2012), which explains why two individuals may experience and perceive the same situation differently. This premise is compatible with the first assumption brought to the study, that each loved one providing care for PWP can experience objective conditions that occur during the caregiving journey, in substantially different ways because of their history and ways of perceiving and experience the world, self and others.

Phenomenological inquiry is concerned with how something is experienced and how such an experience is interpreted by the individual who is having the experience, of what it means to them, and how this can inform the research about the nature of the phenomenon under investigation (Willig, 2012). Therefore, the task of phenomenology is to explicate essential meanings about the phenomenon under investigation. As previously mentioned, consistent with its phenomenological origins, researchers using IPA accept the impossibility of gaining direct or complete access to the participant's subjective experience or psychological world without the use of interpretation (Finlay, 2011). Therefore, access is reliant on the researcher's capability to theorise and make sense of the participant's personal world through a process of interpretative activity (Finlay, 2011; Smith & Eatough, 2012; Story, 2007).

4.3.1.2 Hermeneutics. Hermeneutics is the theory of interpretation (Smith & Eatough, 2007). At the heart of IPA is the notion that humans are “self-interpreting beings” or “meaning-making machines” (Garland & Fredrickson, 2013; Smith & Eatough, 2012). In other words, humans are actively engaged in interpreting the events, objects and the people in their lives. The phrase “sense-making” captures this interpretive act. There are many ways

to interpret life's happenings, and how an individual does this is dependent on, or at least in part, an individual's particular perspective, and always filtered through pre-existing experiential knowledge (Smith & Eatough, 2012). A researcher operating from an IPA approach utilises psychological knowledge and theory to make sense of what is being said by the research participant, and ultimately to achieve a more thorough understanding or meaning of the phenomenon. Willig (2013) distinguishes these levels of interpretation as *empathetic interpretation* and *suspicious interpretation*.

4.3.1.2.1 Empathetic interpretation. Empathetic interpretation seeks to elaborate, amplify and elucidate the meaning that is contained within the data that presents itself, that is, the participants' accounts (Willig, 2013). During this process the researcher attempts to illuminate what presents itself in the data, by paying special attention to the meaning, features and qualities of the data. Consistent with the phenomenological commitment of IPA, the task for the researcher is to establish a frame-of-reference from within, without imposing their own perceptions, personal experiences, judgments, ideas and presuppositions on the data. This would alter the original data and transform its meaning into something entirely different (Story, 2007).

Researchers using IPA both acknowledge and explore the ways in which they are implicated in the process of making sense and constructing meaning of the phenomenon. This involves *bracketing*, or suspending personal judgments, beliefs, taken-for-granted assumptions, biases, expectations and preconceptions; basically what the researcher believes to be as factual in order to concentrate on the perception of the researched issue (Finlay, 2011; Smith & Eatough, 2012; Story, 2007). Bracketing does not mean erasing personal assumptions; rather, it involves a process of recognising their effects, being suspicious of them, interrogating them, and as a result of this being able to hold them more lightly and flexibly without imposing these assumptions on the data (Willig, 2012). The goal here is to

reveal the phenomenon in its purest “lived form” (Willig, 2001). In IPA, researchers must adhere to specific guidelines intended to reduce researcher biases and to keep descriptions as faithful as possible to the original data (Smith & Eatough, 1995; 2007; 2012). The guidelines include several verification strategies designed not only to minimise the possibility of compromising the integrity of the data, but also to optimise the trustworthiness and rigour of the research. The next chapter will outline the verification strategies employed in the present study.

4.3.1.2.2 Suspicious interpretation. In comparison to other qualitative approaches, such as a qualitative descriptive phenomenological approach (Sandelowski, 2000; Vaismoradi et al., 2013) which seeks solely to describe “what is there” or “what is known” to the participant or meaning made by the participant. Whereas IPA goes a step further, whereby a researcher interrogates the data (what the participant is saying) by taking a step back and asking critical questions of the data (Willig, 2013). Examples of critical questions are: “What is the person [research participant] trying to achieve here?”, “Is something leaking out here that wasn’t intended?”, “Do I [researcher] have a sense of something going on here that maybe the participants themselves are less aware of?” (Smith & Eatough, 2008, p. 53). Willig (2013) refers to this process as suspicious interpretation, which is based on the premise that “all is not what it seems” (Willig, 2013, p. 42). Suspicious interpretation requires a researcher to not only question the data, but to utilise their own ideas, and psychological theory and concepts to look beneath the surface of the data (Willig, 2013). Hence, the researcher straddles both an “insider” and an “outsider” approach to research by being both empathetic and questioning (Smith & Eatough, 2007).

4.3.1.3 Idiography. IPA is distinct from other hermeneutic approaches because it focuses on the individual (Finlay, 2011). IPA adopts an idiographic mode of inquiry that involves studying individuals within a particular group. IPA seeks idiographic accounts of

each participant's perspective or point-of-view, how they are making-sense of his or her experiences, before gathering data from multiple participants' perspectives or points-of-view. Essentially, IPA begins with the detailed examination of each individual case or participant, and involves searching for patterns and themes within that case, before moving onto the second case and performing an equally attentive analysis, and repeating the process for subsequent cases. The researcher then continues to search for patterns across cases within a particular group (Smith & Eatough, 2007). Through the process of comparing and contrasting, patterns are consolidated and synthesised into themes, to ultimately convey a general description of meaning or essential characteristics of the phenomenon under investigation (Finlay, 2011; Smith & Eatough, 2007; Willig, 2012).

Intentionality (Moran, 2002), *intersubjectivity* (Moustakas, 1994), and *symbolic interaction* (Denzin, 2008) are also central tenets of IPA. Intentionality relates to "being" in the world and "consciousness" toward the world and objects within the world (Moran, 2002). Intentionality means that the object of one's perception is out in the world, in time and space, and the perception of the object is in the human being's consciousness. From a phenomenological stand-point, the intentional structure of consciousness is about reaching out of one's consciousness to interact with objects and concepts as a means of relating to the world. According to Crotty (1998) in-tending is not about setting intentions, planning or goal setting, rather it refers to *reaching into*, like ex-tending is about *reaching out from*. To this end human beings not only interact with the objects in the world, but also question it, analyse it, embrace it and are altered by it. Intentionality is essential for "phenomenological understandings of meaning-making because it draws attention toward the "directedness," "relatedness," and "involved" nature of our being-in-the-world" (Palmer, Larkin, De Visser, & Fadden, 2010, p.108).

Intersubjectivity is an important aspect of intentionality because the “other” is separate from the self and is co-present in any experiences that share a reality and demonstrate that the world is accessible to everyone. Any human being must explicate their own intentional consciousness through transcendental processes before they can understand something or someone that is separate to them. Human beings base their reality of others on their own experiences. In addition, human beings seek affirmation in their perceptions of reality through social interaction, discussion, argument, and by exchanging ideas, perceptions, and judgments. Through this process perceptions can be altered, refined and validated by others (Moustakas, 1994). Moustakas states that humans crave certainty and validation of their own personal perceptions (possibly to feel in control and safe in the world). However, Moustakas warned that only self-evident understandings enables human beings to communicate intentionally with others, hence why bracketing is important for a researcher in an IPA study.

Interpretative Phenomenological Analysis also acknowledges a debt to symbolic interactionism with its concern for how meanings are constructed by individuals within both a personal and social world (Smith & Osborn, 2008). Like phenomenology and intersubjectivity, symbolic interactionism also stems from the notion “that human beings are not passive perceivers of an objective reality; rather, they are beings that interact with their environment, and they come to interpret and understand their world by formulating their own biographical stories into a form that makes sense to them” (Brocki & Wearden, 2006, p. 88). Put simply, an individual’s reality is shaped by their interactions with their environment and those in it (Moran, 2002).

Social interactionism denotes that meanings occur and are made sense of as a consequence of social interaction (Smith & Eatough, 1996). Hence, in IPA studies, the researcher acknowledges the impact he or she may have on shaping the meaning-made by

participants and vice-versa. To this end, the researcher and the researched co-create meaning and knowledge about the phenomenon under investigation during the research process (Smith & Eatough, 2007, 2012; Smith & Osborn, 2008).

4.3.2 Methods of data collection. IPA is best suited to methods of data collection that invites participants to provide a rich, detailed, first person account of their lived experiences of the phenomenon under-investigation (Frost, 2011; Smith & Eatough, 2012). Face-to-face semi-structured, one-to-one interviews are considered the exemplary forms of data collection for IPA studies (Smith & Eatough, 2012). Semi-structured interviews invite participants to eloquent their stories, thoughts and feelings about their personal experiences of the phenomenon under investigation. This interviewing method suits the IPA approach's idiographic commitments, allowing for rapport to be developed between the researcher and researched, and for each research participants' comprehension of the world to be explored in considerable detail (Palmer et al., 2010).

Semi-structured interviewing lies on the continuum of structured to unstructured interviewing (Smith & Eatough, 2012). Structured interviews are standardised, inflexible and pre-determined in nature. They are typically used in research projects that are deductive in nature (Banister, Bunn, & Burman, 2012). Qualitative projects that are deductive in nature come from a similar school of thought as quantitative research projects and methodologies (Banister et al., 2012). Quantitative methodologies are designed to enhance reliability and typically require the researcher to ask a fixed set of questions in the same order, as well as limiting variation in behaviour between interviews (Smith & Osborn, 2003), which in turn reduces the influence of the researcher on study findings. However, structured interviews have been criticised for not allowing room for anticipatory discovery of a phenomenon and missing salient issues (Willig, 2012) that can be captured in less structured interviews.

At the other end of the spectrum are unstructured interviews, a method that, as the name suggests, the interviewer does not prepare questions that provide structure to the interview. The unstructured interview method is open-ended and in depth, but begins with no more than one preconceived question for the participant: “Tell me about X” (Willig & Stainton-Rogers, 2008). After an opening request for a narrative, the role of the interviewer is to remain a listener, withholding desires to interrupt and sporadically asking questions that may clarify the story (Leavy & Brinkmann, 2014).

In contrast, the semi-structured interview method awards the researcher (interviewer) a greater say in focusing the conversation on issues that he or she deems important in relation to the research project (Leavy & Brinkmann, 2014). The researcher (or interviewer) is free to probe the participants in terms of emerging topics that arise, as well as to explore areas of interest and concerns of the participant (interviewee), and follow-up paths that the participant presented. In doing so, the interviewer may garner information from the participant that had not emerged when using either a structured or unstructured interview method. Typically, the researcher has an idea of the questions he or she would like to investigate, but in keeping with the principles of IPA it is more important to enter the psychological and social world of the participants and to use minimal probes and ask minimal questions. This allows participants the space to discuss what is more important and meaningful to them (Smith & Eatough, 2012).

Furthermore, the semi-structured interviewing method is congruent with not only IPA’s theoretical and philosophical assumptions, but also the present study’s strength-based and existential-humanistic standpoint. Unlike structured interviews, semi-structured interviews allow the participant the freedom to discuss the phenomenon under investigation, in a way that is most meaningful and relevant to them. It allows the participants to take the

“front seat,” to be the expert on themselves, and for the researcher to take more of a “back seat” in the interview.

Similar to a psychotherapist operating in an existential-humanistic framework during a therapeutic encounter, a researcher may utilise micro-counselling skills such as reflections of feeling, reflections of meaning, paraphrasing and summarising (Ivey, Ivey, & Zalaquett, 2010) to reflect the participants’ disclosures and interpretation of meaning back to them during the semi-structured interview. Empathetic reflections and interpretations award the participants an opportunity to hear what they are saying, and a chance to either validate or revise these meanings themselves, or potentially contest the researcher's interpretations (Story, 2007). This is likely to result in faithful interpretations of meaning presented by the participants at the time of data collection, and subsequent analysis. In the present study, it is anticipated that this mode of inquiry would bring the PD caregiving experience to life, both for the participant and the researcher, and ultimately produce a more complete, in-depth, detailed and faithful description of the PD caregiving experience. Through this interview process, the researcher and participant work together in order to gain an in-depth understanding of the participant’s thoughts, feelings and inner psychological world.

As previously mentioned, one-on-one interviews are the most frequently used data collection method. Focus groups and participant diaries are also employed in IPA studies, albeit less frequently (Willig & Stainton-Rogers, 2008). There are relatively few published IPA studies that use focus group discussion (e.g., De Visser & Smith, 2007; Dunne & Quayle, 2001; Flowers, Knussen, & Duncan, 2001; Palmer et al., 2010).

Palmer et al. (2010) state that focus group discussion(s) are less ostensibly suitable for IPA studies because they deliver a considerably more multifaceted interactional environment, and it is problematic to “infer and develop personal phenomenological accounts” (p. 100) of the lived experience under-investigation (which is the aim for IPA). In

fact, Webb and Kevern (2001) argue that phenomenology and focus groups are methodologically incompatible and incongruent, given IPA is fundamentally an idiographic approach to investigation and analysis, concerned with intrapersonal rather than group experiences. However, Bradbury-Jones, Sambrook, & Irvine, 2009 suggest a “means by which individual lived experience can be preserved within a group context”, by engaging each and every individual at an experiential level in the group discussion process and the subsequent analysis (p. 663). That is, ensuring that each participant in the group has an opportunity to share their own personal experiences and to be heard. However, this may prove problematic if some participants are particularly vocal and overpower other quieter more introverted participants (Barbour, 2007). Hence, it is recommended that a focus group is kept to a small number of participants in IPA studies in particular (Bradbury-Jones et al., 2009).

Webb and Keven (2001) also contend that because the primary objective of phenomenological research is to seek the essential characteristics of the phenomena. This approach necessitates that participants describe their experiences in an “uncontaminated” way, free from the researcher’s (or interviewers) preconceptions, prejudices and so forth (Husserl, Rojcewicz, & Schuwer, 1989). The aim in an interview guided by Husserlian phenomenology is for the researcher (interviewer) to assume the position of a detached observer, by suspending his or her prior assumptions (Walters, 1994) and being vigilant not to impose his or her assumptions upon participants and essentially raw data. Similarly, interviews guided by Heidegger also require the researcher to bracket their prior assumptions and understandings. However, the major difference between Husserlian phenomenology interviews and Heideggerian phenomenology interviews is that an interview guided by the Heidegger approach allow the researcher to incorporate his or her understandings and assumptions into the interpretations of participants’ stories (Koch, 1996), only when the raw

data invites it. Heideggerian phenomenology is based on the notion that it is only possible to interpret something according to the interpreter's own lived experience and that this originates from their being-in-the-world (Walters, 1994). It is also based on the premise that that interpretation presupposes some prior understanding on the part of the interpreter (Heidegger, 1962). Given this, Bradbury-Jones et al., (2009) argue that "the Heideggerian concept of being-in-the-world places the researcher in a different relationship to research participants" compared to that of Husserlian phenomenology because the "researcher is engaged in a process of reciprocal interpretation with participants" (p.667) otherwise known as the hermeneutic cycle (see Smith & Eatough, 2007).

Research guided by Heideggerian phenomenology is not concerned with attempting to collect "uncontaminated" participant accounts (Bradbury-Jones et al., 2009). The researcher is not attempting to separate themselves from the participants to arrive at an objective description of the phenomenon under study. Therefore, matters of participant account contamination using focus groups are less problematic in interpretative-phenomenological studies (i.e., IPA) which are guided by Heidegger compared to descriptive phenomenological studies guided by Husserl (Bradbury-Jones et al., 2009). Webber and Kevern's (2001) concerns about the incompatibility of using group methods for data collection with such studies are legitimate for descriptive phenomenological studies because both the researcher and other focus group participants stand to contaminate the data with their own preconceptions, biases and judgments, hence the impossibility of collecting an uncontaminated account.

In keeping with the theoretical commitment to IPA, the present study makes no claims about collecting uncontaminated participant accounts, and furthermore, acknowledges the impossibility of not influencing the original data. The present study recognises that the researcher has the propensity to use their own voice, ideas, knowledge and psychological

theory to interpret and make sense of the data, only when the data invites it (in keeping with the inductive and interrogative characteristics of IPA). As a result, this can enrich the data, but ultimately shapes the analysis and study findings. Thus, focus groups are considered an appropriate method of data collection for the present study.

In addition, there are numerous proposed advantages for using focus groups in IPA studies. Firstly, focus groups do not limit the interaction to “the researcher and participant, but instead support the notion of collaboration and dialogue as being part of the phenomenological endeavour” (Bradbury-Jones et al., 2009, p. 667). To this end, the focus group adds another dynamic, whereby each participant in the group could work together to make sense and bring to life the caregiving experience through both their individual and shared experiences. In turn, the researcher can then make sense of participants making sense of their positive caregiving experiences, both individually and as a group. It has been suggested that this added dynamic could produce a more complete, in-depth, detailed and faithful description of the phenomenon under investigation (see Dunne & Quayle, 2001; Flowers, Duncan, & Frankis, 2000; Flowers et al., 2001; Palmer et al., 2010).

Secondly, focus groups offer the opportunity to cultivate a natural conversation and exchange between participants, bringing the phenomenon under investigation to life through the group’s process of synergy, stimulation, snowballing and spontaneity (Halling, Kunz, & Rowe, 1994; Millward, 2012). Flowers et al. (2001) contend that the particular dynamics of the focus group discussion produce a synergistic effect, and proposed this added to rather than detracted from the analysis.

Thirdly, the group allows participants to hear each other’s stories and experiences, and whilst listening to others this allows time for reflection where they can add their own perspectives, meaning and insights, and subsequently the story unfolds (Bradbury-Jones et al., 2009). This process serves to open up new perspectives, as well as to validate points

being made as shared experiences or meaning (Côté-arsenault & Morrison-beedy, 2001).

Hence, a group discussion may elicit more experiential reflection than a one-to-one interview.

Fourth, the group process can help provide clarification and check for understanding both among participants and between participants and researcher (Bradbury-Jones et al., 2009). Fifth and final, the group process can help the researcher to bracket prejudices because their assumptions are challenged by other group members (Bradbury-Jones et al., 2009; Halling et al., 1994).

In sum, it is argued that focus groups discussion(s) are an attractive method of data collection for IPA studies because not only does this method allow multiple voices to be heard at one sitting from multiple realities, but it may also enrich experiential data that may not have been garnered during individual interviews. The group dynamics stand to enrich rather than dilute accounts of personal experience. In other words, focus group discussion can add something extra to the analysis which would otherwise have been missed at individual interviews (Bradbury-Jones et al., 2009; Flowers et al., 2001; Palmer et al., 2010).

4.3.3 Methods data analysis. The analytic steps, or stages, involved in IPA are not prescriptive, but are flexible and adaptable to better address overarching research questions and aims (Finlay, 2011; Smith & Eatough, 2012; Story, 2007). Nevertheless, step-by-step guidelines (Willig, 2001; Smith & Eatough, 2012) have been proposed for conducting and presenting an IPA research project and were followed in this study. The analytic process of this study is outlined in the following Chapter Five: Method.

As previously mentioned, the researcher plays an active role in the elucidation process of the participants' lived experiences. The researcher makes-sense of the data (interview transcripts) through immersing themselves in the data and engaging in an interpretative relationship with the transcript. Through this process the researcher identifies

meanings in the participants' experiences, and divides into meaning statements or units (Smith & Osborn, 2008). Meaning statements are then organised or clustered into themes and sub-themes, which form study findings. In the write up of findings, themes and sub-themes are reported "in a literary style rich in participant commentaries" from raw data, such as interview transcript accounts (Vaismoradi et al., 2013, p. 398).

4.4 Summary and suitability of IPA for the present study

To summarise, a qualitative method of inquiry was adopted for the present study. It is anticipated that this method of quality addresses gaps in the PD caregiving research, which, until to more recently, is dominated by quantitative methods of inquiry like mainstream psychology. In addition, adopting a qualitative method of inquiry goes some way to giving voice to the loved ones providing care for PWP in research endeavours.

The methodological approach of IPA was chosen because it is best suited to the present study's research focus and broad research question, along with the theoretical assumptions and research assumptions brought to the present study. Furthermore, it is an appropriate methodology for the field of Clinical Psychology in which the present study is occurring. The focus and broad research question is based on the notion that humans have the capacity to find meaning, and transform adversity into an opportunity for growth-ful development. The overall aims were to explore subjective realities of the loved ones providing care for persons with PD, to capture lived experiences that may occur in the PD caregiving journey, and to elucidate sense-making/meaning-making and context implicated in positive experiences and growth-ful development. Hence, the nature of the present study's research focus, aims and questions are subjective, existentially humanistic and transformative in nature. IPA is typically concerned with the same features and is thus highly compatible. Moreover, given IPA's emphasis on sense-making by both participant and researcher, this means that IPA is also compatible with the theoretical underpinnings of the present study.

The present study's research focus, aims and questions are best suited to an IPA approach, and the next chapter will detail how this approach was conducted.

Chapter 5: Method

This chapter will outline the process of conducting the present study. The chapter aims to demonstrate procedural rigour by describing each aspect of the procedures undertaken during the data collection and data analysis phases of this study. This includes how participants were chosen, and how the data was collected, recorded, managed, coded, and analysed. Data collection began following ethics approval from the Australian Catholic University Human Relations Ethics Committee (HREC; Ref. Q2011/12). A copy of the ethics approval letter, dated May 9, 2011 is provided in Appendix G. This chapter will also describe the verification strategies performed, which aim to enhance the credibility and trustworthiness of study findings.

5.1 Participants

5.1.1 Recruitment and sampling procedure. A total of 36 participants were initially recruited for the present research project. Participants were recruited from the local and national Parkinson's Associations (PA), the Australian Catholic University, the local Returned Services League of Australia (RSL), researcher networks, and from other study participants. The project was advertised in the PA's and RSL's newsletters, flyers were distributed at some local PD support groups as well as sent to ACU staff and students via email (see Appendix A for a copy of the flyer and Appendix B for the email advertisement), and word of mouth. Participants were recruited using purposive and snowball sampling strategies. Participants were required to meet the following inclusion criteria: (a) must be the primary caregiver for a person with PD, (b) must be a family member of the person with PD (e.g., a spouse or adult-child), (c) must be aged 18 or over, (d) must be English speaking, (e) the person with PD must be formally diagnosed with PD, (f) the primary caregiver and person with PD must reside in the same household, (g) the primary caregiver must not be receiving extensive in-home assistance, and (h) the primary caregiver must provide some

level of assistance for the person with PD in terms of activities for daily living, (i.e., transportation, housekeeping, or meal preparation).

Of the 36 participants who initially expressed willingness to participate in this study, 33 met the inclusion criteria after the initial screening using the inclusion criteria for phase one. However, a further four individuals were excluded from the study during the data collection phase. One was excluded because she did not meet the eligibility criteria for being a primary caregiver despite earlier information that she did. Another was excluded due to an equipment fault which meant that the interview was not captured and therefore could not be transcribed for analysis. One individual did not consent to having her interview recorded, and the fourth individual was excluded because she did not return the signed consent form. Consequently the final sample comprised of 29 participants in data collection phase one.

Eight participants met the inclusion criteria for the focus group (data collection phase two) at the initial screening. However, two were excluded because they were unable to attend the group as the time, date and location were not convenient. A further three were excluded because although they verbally committed to the group, they did not attend on the day. Consequently the sample comprised three participants in phase two of the data collection. The total sample was 32 participants.

5.1.2 Participant characteristics. Demographic information along with caregiving characteristics are displayed in Table 2. In data collection phase one and two combined participants' age ranged between 32 and 82 ($M = 60$, $SD = 10.80$). The duration of time spent providing care ranged from 1 to 20 years ($M = 8.42$, $SD = 5.69$), and from 1 and 84 hours per week ($M = 26.39$, $SD = 30.73$). Notably, seven participants did not provide a response to either, or both, the duration of time spent caregiving question, or the amount of hours per week question.

Table 2

Participant demographics and caregiving characteristics for data collection phase 1 and 2

<i>Participants' demographics and caregiving characteristics</i>		<i>n</i>	<i>%</i>
Gender	Male	10	31.25
	Female	22	68.25
Age	30 – 69	2	6.25
	40 – 49	2	6.25
	50 – 59	8	25.00
	60 – 69	14	43.75
	70 – 79	6	18.75
	80 – 89	1	3.12
	Not assigned	1	3.20
Highest level of Education	Some secondary	7	21.88
	Secondary completed	5	15.63
	Trade	1	3.20
	Tertiary	10	31.25
	Postgraduate	8	25.00
	Not assigned	1	3.20
	Not assigned	1	3.20
Employment Status	Retired	17	53.13
	Full-time	8	25.00
	Part-time	2	6.25
	Volunteer	2	6.25
	Carer	2	6.25
	Student	1	3.13
	Not assigned	1	3.13
Country of Birth	Australia	24	75.00
	UK	3	9.38
	New Zealand	1	3.20
	Europe	2	6.25
	South Africa	2	6.25
Relationship with PwP	Husband	9	28.13
	Wife	15	46.88
	Widowed wife	2	6.25
	Defacto	1	3.13
	Daughter	4	12.50
	Son	1	3.13
Duration of caregiving (years)	1 – 2	2	6.25
	3- 5	9	28.13
	6 – 10 years	7	21.88
	11 – 15 years	4	12.50
	16 – 20 years	3	9.37
	Not assigned	7	21.88

Note. PwP = person with PD. For additional information on participants' persons with PD characteristics (see Table A1 in Appendix C).

5.2 Design

The study comprised of two data collection phases. Phase one consisted of each participant engaging in a semi-structured interview. The aim of the interviews was to gather in-depth descriptions of first person accounts about their experiences of living with and caring for a loved one with PD. It was anticipated that this method would allow the researcher to address the research question and aims by collecting idiographic accounts from the loved ones providing care (participants) and to gain an understanding of the positive meanings attributed to their caregiving experience, from the participants own perspective, as he or she is living and experiencing caregiving in the real world.

Phase two involved a small semi-structured focus group discussion. The primary purpose of the focus group was to augment the understanding of the lived experience of PD caregiving by gathering supplementary information in order to draw upon insights and to clarify as well as to cross-check information provided by participants during phase one.

The aims of the phenomenological focus group discussion were threefold. First, to enrich the data as a result of participants reflecting on, sharing, and making sense of their experiences at the group discussion. Second, for clarification and drawing upon insights and emergent themes from data collection phase one. And third, to some degree, validate findings and emergent themes derived from data collection phase one. However, this is not to imply an attempt to arrive at ‘the truth’ or to check validity, because clearly this is contrary to the phenomenological philosophy (Bradbury-Jones et al., 2009, p. 667). Rather, Moran-Ellis (2006) emphasise that the meaning of triangulation has been extended beyond traditional, post-positivistic paradigms that view triangulation as a way of using different methods (e.g. mixed method studies that employ qualitative and quantitative methods) in order to increase confidence in the results, “by countering flaws, biases and assumptions brought by one method alone” (p. 45). Instead, it is proposed that using more than one method of data

collection (interviews and a focus group discussion) will assist in the pursuit of ‘knowing more’ and ‘finding out more’ about the phenomenon under-investigation by bring different ways of understanding the data, and to highlight complementary, contradictory or absent findings within it (Moran-Ellis, 2006, p. 45). Hence, the focus group was not aimed to verify data and meanings garnered from phase one, but to add texture to the interpretation of them (Moran-Ellis, 2006).

This qualitative interpretative-phenomenological study, like any other IPA study, is not in pursuit of a definitive truth about experience, or seeking to validate any claim about the experiences or their possible meanings. Rather, this study sought to explore how understanding of meanings can be enhanced by offering a more in-depth, multi-dimensional insight to the complexity of the phenomenon (Palmer et al., 2010). The present study was designed on the works of other IPA studies (see De Visser & Smith, 2007; Flowers et al., 2001; Palmer et al., 2010) that also used in-depth interviews and complementary focus groups in their research.

5.3 Materials

5.3.1 Demographic Questionnaire. A questionnaire (see Appendix D for the intake questionnaire) was constructed to gather (a) caregiver demographics: which included basic details of gender, age in years, marital status, ethnicity, and highest level of formal education; (b) caregiving characteristics: which included asking the participants how long they had been providing care for their person with PD; to estimate how many hours a week they spent caring for the person with PD; and whether they were paid for their caring role (e.g., caregiver’s allowance); and (c) persons with PD demographics and PD characteristics: participants were asked basic information relating to their person with PD’s age, gender, and ethnicity. In addition to this, participants were also asked how long the person with PD had been formally diagnosed with PD and were asked to estimate the stage of the disease.

5.3.2 The interview guides. Semi-structured interview guides were constructed for both data collection phases (see Appendix E and Appendix F respectively). These guides sought to elicit the participants' perceptions of their lived PD caregiving experience, and to ask for clarification and elaboration as required. These guides served to initiate the discussion at the interview(s) and the focus group discussion, but were flexible and whenever possible the researcher allowed the participant to lead the interview.

5.3.2.1 Interview guide for data collection phase one. The interview guide consisted of 11 open-ended questions (see Appendix E). The questions were based upon the works of Netto et al. (2009) and Sanders (2005), who investigated caregiver positive changes and growth associated with dementia caregiving. The interview questions aimed to address the overall PD caregiving experience. Of particular interest were the 'highs' and 'lows' of the participants' PD caregiving experience; the positive and the negative changes that occurred since the person with PD had been diagnosed, as well as the participants' psychological and emotional reactions to the PD caregiving experience. Furthermore, questions related to the desired personal attributes and coping mechanisms that the participant considered necessary for enhancing adjustment and positive caregiving outcomes, with the view to gaining insights, ideas and ultimately hypotheses for predictors of caregiver growth for future research focus.

5.3.2.2 Interview guide for data collection phase two. The interview guide for the focus group discussion (see Appendix F) was informed by the data collected during phase one, some preliminary analysis, and the reflective practice that occurred during this phase. The guide consisted of six open-ended questions. Given the primary objective of the focus group discussion was to draw upon insights from the data collected during phase one, some of the proposed questions were similar in nature to the questions in the interview guide used in data collection phase one.

However, the style of questions differed somewhat, with a stronger focus on the behavioural aspects of caregiving, with the view of eliciting more concrete responses from the participants in order to promote better understanding of their lived PD experience. This was deemed necessary as some of the responses garnered during the interviews were vague, even though clarification was sought at the time of the interview. The remaining questions were based on emergent themes generated at data collection phase one (e.g., perceived lack of psychological and emotional support and professional psychological interventions). The aim of questions proposed by the researcher was to gain a better understanding of the psychological needs of the loved ones providing care for persons with PD. This was done with the goal of determining possible psychological interventions in order to provide better professional support for loved ones providing care for persons with PD.

5.3.3 Audio recorder. The interviews and the focus group were recorded using either a digital audio recorder, or in some cases, the researcher's iPhone. The audio-recordings were downloaded immediately following the interview on to the researcher's computer and deleted from the recording instrument. The audio-recordings were then transcribed verbatim. I, the researcher, transcribed approximately 60% of the interviews and the entire focus group. Professional transcription services (Elance) were hired to transcribe the remaining interviews. Modification to the original ethics approval was obtained for the remaining interviews to be transcribed using a professional transcription service. The transcribing service was bound by strict confidentiality agreements and privacy policies. The audio recordings were uploaded to a private workroom, accessible only to the account holder and the transcriber.

5.3.4 QSR NVivo10 Software Package. The data collected during both phases were stored, managed, and organised using QSR NVivo 10 software package. NVivo is a

qualitative data analysis software program that supports qualitative research projects (QSR, 2012).

5.4 Procedure

5.4.1 Data collection phase one. During the initial screening process, it was determined whether the participants met the inclusion criteria. The initial screening process was identical for both data collection phase one and two. Once the potential participants learned about the study through the various recruitment modes (e.g., flyer, email, newsletter or social network), they expressed their interest in participating in this study by contacting the researcher either by email or telephone. During the initial contact, each potential participant was introduced to the researcher and informed of the nature and purpose of the study, before initial screening took place. The inclusion criteria checklist was used to ascertain whether each participant met the inclusion criteria.

For those who were eligible, a mutually convenient date, time, and place were agreed upon between researcher and participant in order to conduct the interview. Participants were sent an information pack either by email or post depending upon their preference. The information pack included an information letter (see Appendix H), consent form (see Appendix I), and the intake questionnaire (see Appendix D).

For telephone interviews, a stamped addressed envelope was provided for the participant to return the signed consent form and completed demographic questionnaire to the researcher. For all face-to-face interviews, participants either brought the signed consent form and completed demographic questionnaire to the interview, or signed and completed the consent forms and demographic questionnaire at the time of data collection.

Consistent with IPA methodology, the interview guide was developed essentially to prepare the researcher for the interview. This preparation provided time for the researcher to concretise thoughts and ideas about topics the interview may cover, as well as time to

anticipate possible difficulties that may be encountered during the interview, and to consider appropriate wording of the questions. Provision was taken at the time of constructing the questions not to reveal the research question. For example, questions pertained to both positive and negative aspects of caregiving were included, with the view to concealing the nature of the study's aims and research question.

This preparatory process aimed to build the researcher's confidence for conducting the interviews, as a result of planning and memorising the questions in advance. The intention of this was to enhance the researcher's ability to pay attention, be present, and immerse oneself in participants' internal frame-of-reference. Whilst this was the intention, this did not always translate into practice, especially during the earlier interviews (see Appendix U for more details on this. Appendix U outlines reflections of practice at each stage of this research project, including the early stages of choosing the project topic, choosing the research and methodological approach; and at each stages of data collection and data analysis.

Consistent with the IPA approach, this study was reflexive in nature (Finlay, 2011; Smith & Eatough, 2012). Finlay and Gough (2003, p. ix) used the term *critical self-reflection* to capture the relationship between reflection, that is "thinking about" something after the event. In contrast, reflexivity is termed as a "more immediate, dynamic and continuing self-awareness" (Roulston et al., 2008). These terms, and actions were adopted in the present study. During this entire research project, the researcher kept a journal log (see Appendix P for an extract of the journal).

After the first interview was conducted, the interview process was critically reflected upon. When listening back to the interview as well as reading the interview transcript, it was deemed by the researcher and supervisors that the researcher was too directive and had conducted the interview more like a structured interview than a semi-structured interview.

This was not consistent with the IPA approach, which allows the interviewee to lead the interview and discuss what is relevant to their lived experience (Finlay, 2011; Smith & Eatough, 2012; Story, 2007).

At the first interview, some of the questions (not limited to the ones on the interview guide) were deemed to be explicit and loaded, with the interviewer leading the participant at times. For example, participant one, Darren, stated “But the vast majority of people with Parkinson’s, they need to be able to manage what they are going through, and to manage their lives for themselves. So if there is something that they can’t do then, they need to find something they can do, and find something else for them to do”. The interviewer responded with a reflection of meaning “to have a sense of independence and a sense of meaning, in their own life”. The person with PD (Darren’s wife, who was present at the interview) responded “Yes you need to have something to do for the day when you wake up in the morning”. Given this study was investigating the positive aspects of caregiving such as finding meaning in the caregiving situation, the interviewer’s statement could be considered leading, and imposing her own assumptions and biases onto the research participants, and thus ultimately shaping the interviewees to lean towards the positives of PD.

Upon reflection and discussion with the supervision team, a decision was made to change the opening question, making it more open, to set the precedent for the interview and award the interviewee the freedom to lead the interview in a direction that was most meaningful to them. For example, the first question became more of a general opening “Tell me about your caregiving experience to date”, “What has it been like for you since PD came in to your life?”, or “Tell me about your experience since your loved one was diagnosed?”, in contrast to the original opening question “Since (person with PD’s name) was diagnosed with PD, what would you say has been the hardest thing that you (and person’s with PD’s name) have had to come to terms with?”. This re-drafting is consistent with Smith and Eatough

(2012) who argue that first drafts of questions are often too explicit and may need redrafting to become gentler and less loaded.

The researcher conducted all the interviews. Of the 29 interviews that were included for analysis, 23 were telephone interviews and 6 were face-to-face interview. Of the face-to-face interviews, three were conducted at the participants' homes; two were conducted at the researcher's workplace; and the remaining one was conducted at the participants' workplace. The setting of the interviews adhered to guidelines outlined for conducting qualitative research interviews (Gillham, 2005; Wengraf, 2001).

The duration of the interviews varied between 26 and 90 minutes, with an average interview lasting 40.8 minutes. Participants were informed prior to the interview that only their presence was required, not the persons with PD. Although in one instance (interview number one), the person with PD was present at the face-to-face interview, and consequently engaged in the interview.

At the beginning of the interview, participants were reminded of the nature and purpose of the study and it was reiterated that the study was aimed at exploring their overall experience since their loved one was diagnosed with PD. Participants were provided with the opportunity to ask questions prior to, and during the interview. At times during the interview participants were asked to clarify and elaborate on phrases and any words that the interviewer did not understand or thought were somewhat ambiguous requiring further clarification.

Probes were used throughout the interviews to assist in gaining a deeper understanding of the participants' frame-of-reference. For example, when required participants were asked "Can you tell me more about that?", "What was that like for you?", or "How do you make sense of that". At the conclusion of each interview, the interviewer invited each participant to email or make contact if they thought of anything else they wanted

to mention. One participant did email the researcher, which served to concretise and clarify themes discussed at her interview.

At four of the telephone interviews it was evident that the persons with PD were in the background because the interviewee either referred to them or asked them a question in order to provide relevant information to the researcher. Steps were taken by the researcher to manage the challenges and to minimise the possible implications on study findings (discussed in more detail in Chapter 8, section 8.3 Methodological Limitations). For example, at the commencement of the telephone interviews, the researcher opened the conversation by questioning “Are you sitting comfortably, in a private space so you can speak freely?” The researcher reiterated that it was not necessary for the person with PD to be present. In two instances the interviewees stated that their person with PD was indeed present and then said they had closed the door, or moved to a different room for privacy. For the other two interviews, the interviewees said they could speak freely, but then the interviewer heard voices in the background and clarified who was present at the time of the interview (notes were made for consideration for the analysis). The researcher asked if there was a better time to call so they could speak freely and they said they were not concerned about their person with PD overhearing. One interviewee commented “we share everything”, and the other stated that the person with PD had entered room (apparently for something) then left. It appeared that the person with PD was present for minimal amounts of time during the interview rather than remaining for the entire interview. Therefore, it is expected that the brief presence of the person with PD will have minimal impact on disclosure at the interview and ultimately present study findings.

5.4.2 Data collection phase two. The focus group was designed and conducted based on guidelines outlined by Barbour (2007), Millward (2012) and Palmer et al., (2010). The inclusion criteria was identical to collection phase one, however with the additional of

the clause, “a participant was not eligible to partake in data collection phase two if he or she participated in data collection phase one”. This rule was applied to facilitate validation of data collected in phase one, by means of comparing it against data collected from a different sample.

Prior to the group, the information packs were sent to the potential participants, again including the information letter (see Appendix J), consent form (see Appendix K), and intake questionnaire (see Appendix D). In addition, a map and directions to attend the focus group locations were sent (via email), and a reminder email was sent prior to the meeting date with the group.

The researcher conducted the focus group discussion. A note-taker was present to take notes in case there was a malfunction with the recording device. The focus group discussion was held at the ACU Brisbane Campus. An appropriate room was selected in accordance with the guidelines for conducting a focus group by (Barbour, 2007; Hennink, 2007; Kitzinger & Barbour, 1999; Millward, 2012; Wilkinson, 1999). Prior to data collection each participant completed the intake forms and consent forms were signed. Refreshments were provided, and the participants were invited to introduce themselves, and share some information about themselves, (e.g., why they had agreed to attend the group), which served as an ice breaker. The note-taker was introduced to the group and her role was explained. Expectations and terms of confidentiality for the group (including the note-taker) were outlined by the researcher.

Participants were informed that the focus group discussion was semi-structured. They were told that they would each get a chance to answer each question, and were encouraged not to interrupt each other. They were encouraged to ask each other questions, and to bring up topics that they perceived were relevant. Participants were also reminded about the nature

and purpose of this study, and were provided an opportunity to ask any questions of the researcher.

As expected, the group was more structured at the beginning with greater reliance on the interview guide (Barbour, 2007; Millward, 2012; Palmer et al., 2010). Although shortly into the group discussion the dynamic changed and the discussion became more free-flowing, natural, and conversational. Participants began asking each-other questions. This natural flow is supported by Smith and Eatough (2012) who ascertained that avoiding rigid adherence to a guide, and allowing the participants to take the lead in the discussion can result in pertinent and valuable insights. Similar to the interviews, probes were used to seek clarification. The duration of the focus group discussion was two hours.

5.5 Data Analysis

Data was managed in accordance with conditions stipulated through the ethics approval process. Any identifying characteristics were changed or omitted in any printed documents (e.g., transcripts and extracts in the body of thesis). All materials and documentation relating to each participant was marked with an individual pseudonym allocated by the researcher. The materials and documentation included interview audio recordings, interview transcripts, field notes, portraits of the participants and the data stored in NVivo. All materials and documentation was kept in a locked filing cabinet on ACU premises. Documentation that disclosed the true identity of each participant (the consent form and demographic information) was stored separately in another locked filing cabinet.

The data analysis followed guidelines for conducting IPA outlined by Smith and Osborn (2003) and Smith and Eatough (2012), and also drew on inductive Thematic Analysis (TA) as described by Braun and Clarke (2006). Previous IPA research studies (see Cridland et al., 2014; Wong et al., 2009) have also used Braun and Clarke's (2006) recommendations for TA for analysing data.

In the present study, the six phase analytic process involved: (1) Immersion and familiarisation with the data, (2) Generation of initial codes, (3) Identification of potential themes, (4) Reviewing and refining themes, (5) Defining and naming themes, and (6) Writing the findings section of this thesis. These phases (outlined in more detail below) were not performed in a linear fashion, rather initial stages were returned to, in a back and forth manner, throughout the entire analysis.

There are many similarities in TA and IPA. Indeed, some of the analytic steps of TA and IPA are identical (*immersion and familiarisation with the data*) (Braun & Clarke, 2006; Smith & Eatough, 2012). However, there are also differences. A major difference is that IPA is considered a methodology, an entire framework for conducting research, and as such is theoretically bounded. Whereas TA is considered as a method, that is a technique for collecting and analysing data (Braun & Clarke, 2006). TA can be used to analyse most types of qualitative data (e.g., interview transcripts) and is not wedded to any pre-existing theoretical framework. Therefore, TA can be used within different theoretical frameworks (Braun & Clarke, 2006) such as the present, and previous IPA studies (Cridland et al., 2014; Wong et al., 2009). Another advantage is TA can easily be performed in NVivo (Bazeley, 2013) which, to reiterate, was used in the present study.

Whilst both IPA and TA involve coding and theme identification and generation, the processes are somewhat different for each. In the present study, when merging steps of TA outlined by Braun and Clarke (2006) with recommendations for IPA, careful attention was paid to ensuring each analytic step was in keeping with the inductive, idiographic, and phenomenologically informed framework for IPA.

As previously mentioned, the initial analytic phase (*immersion and familiarisation with the data*) are the same in both IPA and TA. Although the procedure for the following phase (*code generation*) is somewhat different. In TA, coding commences after a process of

data familiarisation. This involves the researcher noting any initial analytic observations about each data item (interview transcript) and then, the researcher does the same across the entire data-set (all participant interview transcripts). The researcher either collates the data relevant to each code as they code, or they collate all the relevant data at the end of the coding process (Braun & Clarke, 2006). Whereas in IPA, coding involves a process of ‘initial noting,’ whereby the researcher notes down his or her initial analytic observations about the data on each data item (interview transcript). These notes are brief commentaries on the data rather than succinct codes (Smith & Osborne, 2003; Smith & Eatough, 2012). This means that initial noting in IPA lies somewhere between data familiarisation and coding in TA (Smith, Flowers & Larkin, 2009).

In the present study, initial notes and commentaries were made on the transcripts as outlined by Smith & Eatough (2012). Then, data (transcripts) were uploaded into NVivo and initial inductive coding was performed in NVivo as outlined by Braun and Clarke (2006). Careful attention was paid to ensuring this phase was in keeping with the inductive and idiographic nature of IPA.

In terms of procedures for theme development, TA focuses mainly on patterning of meaning across participants, which involves developing each stage of analysis across the entire dataset. Procedurally, themes are developed from the codes across all data items (interview transcripts). In contrast, IPA focuses on both the unique characteristics of each individual participant, and on patterning of meaning and themes across participants. Procedurally, initial noting and progresses to developing themes for each data item (interview transcript) before moving on to the next transcript (data item).

In the present study, drew upon Braun and Clarke’s recommendations for inductive theme generation, and thoughtful consideration was paid to the unique characteristics of each individual participant as well as patterning of meaning and themes across participants.

Procedures for inductive theme generation outlined by Braun and Clarke (2006) are in keeping with the inductive, idiographic and phenomenologically-informed nature of IPA. Furthermore, Braun and Clarke's (2006) well-defined guidelines were followed in terms of theme constitution, identification and definition (explained later in section 5.3.3) as well as drawing upon Smith and Eatough's (2012) guidelines to ensure primacy was given to 'experience' and 'meaning' (Holloway and Todres, 2003) in keeping with IPA's recommendations. The six stages of the analysis are now described in detail.

5.5.1 Phase one: Immersion and familiarisation with the data. This phase began during the recruitment, screening and data collection phases. Multiple preliminary analytic tasks were performed by the researcher, and included: (a) conducting the interviews and focus group discussion; (b) developing 'portraits of the participants'; (c) developing visual mind-maps of participants; d) transcribing the focus group discussion and a substantial proportion of the interviews. The interviews that were transcribed by the professional transcription company were checked for accuracy, which provided an opportunity for familiarisation of data; and (e) keeping a journal of the entire analytic process.

5.5.1.1 Development of 'Portraits of Participants'. Preliminary data analysis began at the time the participants initially expressed their interest in the present study, which was considered the 'initial point of contact'. 'Portraits of participants' were developed (see Appendix M for an example of a portrait of the participant) for multiple purposes throughout the analysis, interpretation, and the write up phase of the present study. First, to aid the researcher in familiarisation with each participant. Second, as a means of capturing pertinent and valuable contextual information garnered about each participant at each 'point of contact' with each participant (e.g., the initial telephone or email screening, the interview, or focus group). Awareness of context during the analysis is thought to contribute to meaningful and appropriate interpretation of what has been observed, or told (Bazeley, 2013). Third,

writing a portrait for each participant was a practical way of reflecting on the research interview conducted with each participant, and served to make the researcher's preconceptions and reactions to the participant explicit, and their potential influence on the project at the start of the analytical process. It was anticipated that this process of reflection would assist in reducing the likelihood of unnecessarily imposing the researcher's subjectively experience, assumptions and biases on the data, and ultimately skewing study findings. Rodham, Fox, and Doran (2015) argue the researchers' openness to participants' responses, critical self- reflection about their own reactions to participants' responses and a curious attitude are necessary conditions to avoid a researcher bias in interpreting meaning.

The portraits included the following: (a) *Specifics about initial point of contact*, including environmental information such as date, time and mode of contact (e.g. email, telephone); how each participant heard about the study; information about reasons for partaking in the study; or preferred meeting place for the interview (e.g., eagerness to meet at a coffee shop); or if a participant asked what they could do to prepare for the interview. All this information conveyed messages that facilitated a better holistic understanding of each participant. For example, individual's reasoning for partaking in the study conveyed messages about possible underlying motivations of behaviour and an internal frame-of-reference, which could be called upon during the interpretive phase of data analysis; (b) *Observations at each point of contact*, which involved recording any observations about each participant's presentation. Bazeley (2013) emphasises that observation helps to balance the perspective gained from participants, such as whether self-report was congruent with body language, or if the participant appeared to be concealing information. Silverman (2000) argues that the researcher should record everything that is observed as well as what is said by the participant. Hence, portraits served to capture tacit knowledge which may have otherwise been lost. Observations about each participant's presentation were guided by a

mini Mental State Examination (Groth-Marnat, 2009). This encompassed participant's presenting manner, punctuality, attire, patterns of disclosure of information and speech, body language, affect and mood, attention and concentration, rapport (e.g., easily established), attitude towards the interviewer, assumptions about possible underlying beliefs, schemas, values, existential concerns, and future orientation. Relevant information about the participant's personal circumstances which may have contributed to presenting manner and self-report at the interview was also recorded. Essentially, everything that may be relevant for explaining findings was recorded. (c) *Observations about the interview*, for example, who was present at the interview, and or if there were interruptions at the interview (also noted on the transcript; (d) *Initial analysis of themes*. Early ideas about patterns and themes for each participant were recorded, such as the main caregiving problems discussed at the interview; (e) *Initial interpretations*, notes were made about early abstract and conceptual interpretations based on each participant's self-report and presentation. Furthermore, novel or surprising information, further hypotheses and questions that were generated as a result of points of contact were also recorded; and finally (g) *Reflection(s) of Practice*. At the end of each portrait, a reflection of practice was written based on researcher's experience at the interview. This included any reflections on the researcher's reactions or emotional response to the participant, what the participant was saying, and any counter-transference issues that surfaced during the contact with the participant. These portraits were de-identified, stored in NVivo and called upon at various phases of the analysis to assist in gaining a deeper and holistic understanding of the participants' experiences.

5.5.1.2 Development of visual mind-maps. Visual mind-maps for each participant were developed (see Appendix M for an example of a visual mind map). Mind-maps provided a visual holistic and contextual representation of information garnered from the preliminary analytic tasks. The mind-maps included background information and

demographics, caregiving experience, as well as initial thoughts, ideas, themes, and early interpretations generated from the process of ‘active’ reading. These visual maps were repeatedly referred to during the phases of analysis, with the aim of the researcher re-familiarising oneself with the ‘whole’ participant. Furthermore the transcripts, portraits and mind-maps were useful for both within-case and cross-case analysis as recommended by Bazeley (2013).

5.5.1.3 Transcriptions. Transcribing is an excellent way for the researcher to become familiar with the data (Bazeley, 2013; Braun & Clarke, 2006; Smith & Eatough, 2007). Bird (2005) states that the transcribing of interviews is an essential part of data analysis and in itself is acknowledged as an interpretative act (Bazeley, 2013). Therefore, to reiterate, I, the researcher, transcribed a substantial amount of the interviews and the entire focus group. Notwithstanding, all transcriptions provided by the professional transcriber were checked by the researcher for accuracy against the audio-recording. Whenever possible the interviews were transcribed promptly after they were conducted. Interviews were transcribed verbatim in a Microsoft office word processing document (see Appendix O for an example transcript extract, and Appendix N for the key of transcription conventions). Transcripts were de-identified and stored in NVivo for subsequent stages of the analysis.

5.5.1.4 Reading and re-reading transcripts. The next preliminary analytic task was reading the entire (whole) transcription to gain a holistic impression of the account, as recommended by Bazeley (2013), Smith & Eatough (2012) and Willig (2012). The audio-recording was listened to while reading the transcription. Any contradictions or incongruence between the participants’ self-report and tone of voice, hesitations, and silences, were noted in the portraits and mind maps for that participant, a further interpretive act. Arguably, having conducted and transcribed the interview(s), one should already be familiar with the data. However, it is considered imperative for the analyst to remind and re-

familiarise oneself of the depth and breadth of content, even if the analyst (in this case the researcher), transcribed the interview (Bazeley, 2013).

The aim of this analytic task was to form a sense of the whole (participant), and capture the essential nature of what was being spoken or observed before breaking down the detail within it (Bazeley, 2013), that is, the ‘parts’ that make the ‘whole’. In other words, given the significance of the hermeneutic circle in phenomenological interpretation, it was important to be cognisant of the relationship between the whole, such as the entire account of the experience; and the parts such as individual words, sentences or phrases that describe particular aspects of the experience (Willig, 2012). Furthermore, going through the process of reading the transcript, while listening to the audio-recording of the interview, provided an opportunity to critique the researcher’s performance as an interviewer, with regards to technical and interpersonal skills.

This analytic task provided an opportunity to evaluate whether rapport was established, appropriate nuances captured, prompts and probes appropriate to garner richness of data, and to interpret why certain questions were omitted or not asked (Guest, MacQueen, & Namey, 2012). These reflections and interpretations were recorded in the ‘reflection of practice’ section of the ‘portrait of participant’ document (see Appendix L). Consequently, modifications to interview style were made at subsequent interviews with the view to enhancing the quality of data collected.

5.5.1.5 Active reading of transcriptions. ‘Active reading’ of each transcriptions was undertaken, paying close attention to what was said by the participant. This involved searching for meaning, patterns, and themes (Bazeley, 2013; Braun & Clarke, 2006; Smith & Eatough, 2012). The comments function in Microsoft word was used to record initial comments, ideas and themes, thoughts, ideas and so forth. This process of writing the transcripts, reflecting, writing the portraits and reflecting was performed to assist in the

comprehension of the meaning structures of the text in preparation for the next stage, being the initial coding and subsequent generation of themes.

5.5.2 Phase two: Generating initial codes. This phase involved the “breaking down phase”, that is, moving from the ‘whole’ (each participant transcript or participant as a coherent whole) to examining the ‘parts’ (Bazeley, 2013). This process encompassed returning to the start of the transcript and examining each line of the text more closely, in a line-by-line fashion (Bazeley, 2013; Smith & Eatough, 2012; Willig, 2012). Consistent with phenomenological research, the primary stages of the analysis were inductive and were only concerned with what presented itself in the data. In other words, the researcher stayed engaged with all the data available without dismissing any part of it and without deciding beforehand which part of the data may be more or less important, relevant or significant (Willig, 2012).

Extracts from the transcription were coded based upon what appeared ‘interesting’, ‘relevant’ and ‘meaningful’ (Braun & Clarke, 2006; Smith & Eatough, 2012). Willig (2012) and Smith and Eatough (2012) refer to this stage of the analysis as a ‘descriptive stage’. The aim was to capture the finer nuanced of meaning communicated in each line of the text as well as coding a long enough passage (in-context) without clouding the integrity of the coded passage (Bazeley & Jackson, 2013). That is, the codes were titled or named to capture substance and meaning of participant’s words.

Extracts were not coded by ‘in vivo’ or ‘indigenous’ methods (Corbin & Strauss, 2008) whereby the name or title of the code is derived directly from the data (data-driven) and captures the ‘exact’ expression of the participant (Bazeley & Jackson, 2013). Rather the title of each code was not derived from an individual participant’s exact words, but rather, the title of each code was chosen to best represent words used across all participants. This was done in order for the codes to be representative of data, whilst respecting all participants’

comments equally, rather than favouring one participants use of language and meaning over another (see Table A3, Appendix Q for an example of generation of initial codes from interview transcript).

During this initial coding phase, Braun and Clarke's (2006) recommendations were followed which included: (a) coded for as many potential themes/patterns as possible and nothing was dismissed as irrelevant. This was evidenced by the substantial number of initial codes generated at the end of the process (1500+ codes); (b) coded extracts of data in context, that is, kept some of the relevant surrounding text; and (c) individual extracts of data were coded multiple times for multiple initial codes.

Once coding of the first transcript was completed, the researcher then worked systematically through subsequent transcripts. The initial code names were modified, (still grounded in the words of the participants) to more general titles as the coding progressed, to capture what other participants have said or similar nature to existing coding. For example: originally coded at *"can't take the person with PD's independence away"*. This was referenced by many participants, (although obviously language varied) modified to *"person with PD needs to maintain independence"*, but modification still captured the meaning. Modifications were recorded in the journal log (see Appendix P for an example extract of the journal log) throughout the coding process.

5.5.2.1 Coding log/journal. Throughout the coding phase a 'coding journal log' was kept to record descriptions of codes used and categories developed. The journal was stored in the memo function in NVivo. The journal also comprised details of analytic thoughts, ideas, speculations, and interpretations in light of increasingly sophisticated judgements, developed by the researcher as a result of the immersion with the text and coding process.

These speculations and interpretation were considered in context of psychological theory during the final stages of the analysis and during phase six, the write up of Chapter

Seven (Discussion) when explaining and interpretation the findings of this study. Hence, the journal not only also served as an audit trail (Bazeley, 2013; Braun & Clarke, 2006; Guest et al., 2012; Richards, 2009; Silverman, 2004; Smith & Eatough, 2012) but also assisted in the process of turning private thoughts into public knowledge and became a vital source of later analysis (Hammersley & Atkinson, 2007)

5.5.2.2 *Reaching coding consensus.* First and second independent coders were sourced to verify the reliability and consistency of coding, and ultimately to ensure trustworthiness of analysis. The first was sourced through a professional qualitative research organisation. She is an expert in qualitative research and has expertise in data analysis from both an IPA and TA approach. The second was the previously mentioned note-taker at the focus group discussion in this study, and served as a supplementary measure. She has experience in qualitative research. Each inter-rater was instructed with the philosophy behind being an inter-rater and the chosen analytic approach for the present study. Each coder was asked to code six interview transcriptions (Marques & McCall, 2005).

A sample of six transcriptions were selected at random, by pulling names out of a hat, and coded by both independent coders. Table A4 (see Appendix R) shows an example the first independent coders initial coding matched against the researchers coding. As evidenced in Table A4 coding was not exactly the same, rather in many cases each assigned a slightly different name or label to the code (or node), which is expected (Smith & Eatough, 2012; Willig, 2013). This is consistent with philosophical underpinnings of this study, and in turn the philosophical assumptions underpinning IPA that individuals can see the same objective conditions, in this instance the same text within a transcript, in different ways. Even when the phenomenological commitment of IPA is honoured, in terms of bracketing assumptions, adopting an attitude of openness and curiosity when coding the text, and making every effort to ensure codes are actual representations of the text (Rodham et al., 2015).

Nevertheless, when comparing the first independent coder's coding against the researcher's coding, each coding was very similar, and stayed closed to the participants' words. Whilst there were some variations in the name or label assigned to the codes, there was agreement on content (see Table A4, Appendix R). This meant that there was no disagreement that needed resolving. It was deemed, by the professional coder and the researcher, the variations or discrepancies between coding, were attributable to the researcher's lack of experience and tendency towards data reduction rather than data retention (Richards, 2009), which manifested in categorising the text into themes prematurely, without reconstructing the original experience (in participants' accounts) descriptively in the participants' own words. The difficulties with coding are discussed in more detail in Appendix U. As previously mentioned, Appendix U outlines the researcher's reflections of practice throughout the entire research project.

In instances where there were discrepancies, most often it was deferred to the professional coder because she had most experience in IPA analysis. However, Rodham et al. (2015) questions whether novice researchers unnecessarily concede their interpretation being substandard, or less correct, compared to their more experienced colleagues. Although in the present study, and as evidenced in Table A4, this did not seem to be the case, the discrepancies were largely due to the researcher's inexperience in coding rather than differing opinions regarding initial coding. Discrepancies reduced over the course of coding training.

The major aim of collaboratively working through this process of achieving coding consensus was to ensure that the emphasis of the analysis was not weighted towards the researcher's own background or interests (Rodham et al., 2015). In addition to using two inter-rater coders, another verification strategy was employed. The researcher's associate supervisor also assisted in the verification and confirmation of code names (and later

themes). This involved checking accuracy of the coding, as well as evaluating the quality of the data collected. These checks can be seen as an indicator of the trustworthiness of the coding process, and as contributing to the validity of the conclusions drawn from the codes (Bazeley, 2013). Once coding consensus was reached, the remaining transcriptions were coded, and resulted in over 1500 initial codes.

These initial codes needed to be reduced, or organised to better reflect the structure of the entire data set. Before moving onto this next phase, the entire list was examined, and a ‘clean-up’ process occurred, as it was apparent that some codes were too specific or narrow, and could be more general to include other coded extracts with similar meaning with other codes. Thus some codes were merged, and replaced by the new synthesised code with a more generalised name (Bazeley, 2013). Codes were not abandoned, until the next phase of analysis: ‘the identification and refining of overarching themes’. To be clear regarding the use of the words Theme(s) and Code(s): Themes refers to overarching constructs that comprise of the previous coding methods, aforementioned. That is, previous Codes are subsumed within overarching Themes. The process of the development of these Themes using previous Codes/coding processes are described in the following sections in detail.

5.5.3 Phase three: Searching for themes. This phase refocused on the analysis at the broader level of themes, rather than codes. The term, *theme*, was used in this project to describe an aspect of the phenomenon that is essential to the nature of the phenomenon (Braun & Clarke, 2006). It has been defined as an outcome of coding, categorisations and analytic reflections (Saldaña, 2009). Decisions were made about what constituted a theme, which was influenced by the present study’s assumptions and research question. A theme is defined by Braun and Clarke (2006) as a way of “capturing something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (p. 82). Both IPA, and thematic analysis (TA), the researcher’s

judgment is relied upon to determine what constituted a theme (Braun & Clarke, 2006; Smith & Eatough, 2012).

According to Braun and Clarke there is no hard-and-fast rule about what proportion of the data set needs to display evidence of the theme for it to be considered a theme. They maintain that some level of flexibility is required and deemed rigid rules ineffective (Braun & Clarke, 2006). Braun and Clarke also note that there is no right or wrong method for determining prevalence but rather what is important is consistency in how you do this within any particular analysis.

In the present study decision making about what constituted a ‘theme’ was based on the ‘keyness’ of a theme, and was not necessarily dependent on quantifiable measures (how often it was reported) but rather on whether it captured something important in relation to the overall research question. Braun and Clarke (2006) cautioned that the number of times referenced did not necessarily mean the theme itself is more crucial, than one that was referenced once or a few times. In accordance with Braun and Clarke’s guidelines, as well as the philosophical underpinnings for IPA, in this study, the generation of a theme was not determined by the amount of space it took up in the transcript text, (e.g., 50% interview compared to one line). Neither was the generation of a theme solely determined on prevalence (most commonly referenced) of codes (or nodes) within and across all interviews and focus group. Rather a theme was generated based on meaningfulness or importance to the research participant as well as the research question and aims. Thus, a key or meaningful statement could become a theme, even it was only mentioned a few times, or even once, by one participant.

Prior to commencing this stage, a broader perspective of the data was taken and the portraits and mind-maps were re-visited to re-gain a holistic and contextual sense of each participant. This phase involved sorting the codes into potential themes, and collating all the

relevant coded data extracts within the identified potential themes (Braun & Clarke, 2006). In IPA this process is most commonly referred to as clustering (Smith & Eatough, 2012).

During the generation of themes stage, the researcher constantly reflected about relationships and commonality of emerging themes and patterns in the data during the preceding analytic tasks. This stage three involved searching for themes, looking for relationships between codes, between themes, and between different levels of themes (e.g., main overarching master themes and sub-themes within master themes). In this study the entire list of codes generated in phase two was organised by grouping (Bazeley, 2013; Braun & Clarke, 2006) or clustering (Smith & Eatough, 2012; Smith & Osborn, 2003) the codes into potential themes, based on 'keyness', meaning as well as most commonly referenced (Braun & Clarke, 2006). This process, performed in NVivo, involved the following six mechanical tasks (see Table A5, Appendix S): (i) Reviewing the initial code list, noting the most commonly referenced codes and how many participants had referenced these codes; (ii) Creating a list of the most common codes, whereby most reference codes across the transcripts were collated into a 'most common nodes' folder (Bazeley, 2013); the cut off was 15 nodes; (iii) Examining the 'most common nodes' folder, looking for themes and patterns; (iv) Identifying the emerging connections and relationships between both commonly referenced and key codes. (v) Gathering all data relevant to each potential theme by copying and pasting in to each potential theme folder. That is, putting together all relevant coded data extracts within the identified themes, including those referenced infrequently. Notably, many of the codes fitted into more than one theme, thus these codes were copied and pasted into both theme folders; and finally (vi) Generating a list of themes, which were refined at the subsequent stages of the analysis.

Consistent with the IPA approach, this 'searching for themes' phase, was more interpretative than the initial coding phase. The researcher called upon psychological theory

(i.e., the theoretical models of AAD, PTG and the revised meaning making model) in an attempt to capture more concisely the psychological quality inherent to the participants' own words (Smith & Eatough, 2012).

5.5.3.1 Development of thematic maps. At this third stage of the analysis, thematic maps were developed (see Appendix T for two examples of thematic maps). Thematic maps are visual representations that serve to assist the researcher or analysts in generating themes, and in visualising relationships between patterns and themes within the data (Bazeley, 2013). In this study, the development of thematic maps assisted the researcher in transferring initial codes and sub-codes into themes/sub-themes or combining codes or sub-codes to form a theme/sub-theme. This process facilitated the identification of themes and patterns across the entire data set (interviews and focus group), and moreover, helped the researcher to see new relationships and propose explanations or interpretations for these themes or findings

5.5.4 Phase four: Reviewing and refining themes. Once potential themes were devised, they were refined and revised. During this and the previous phase, it was evident that some themes were not actual themes. Hence some themes were dropped either because they did not fit well within the emerging structure or because, within the emerging analysis, they did not have a strong enough evidence base (Bazeley, 2013; Braun & Clarke, 2006; Smith & Eatough, 2012).

Two levels for reviewing and refining themes were employed. The first level involved reviewing the coded data extracts, and ensuring collated coded extracts formed a coherent pattern (Braun & Clarke, 2006). If the coded extracts did not fit with the theme, they were moved to another theme, or the theme was reworked. The second level involved a similar process, but in relation to the entire data set, themes 'accurately' reflected the meanings evident in the data set as a whole (Braun & Clarke, 2006).

5.5.5 Phase five: Defining and naming themes. The theme names constantly evolved and changed whilst conducting the analysis. However, this phase involved final definition and naming of themes and sub-themes based on the ‘essence’ of what each theme was about. This phase involved organising the themes so that each theme was internally coherent, consistent, and distinctive; as well as actually reflecting the overall story or present study findings.

The researcher consulted with the associate supervisor of this project, who checked that themes identified were congruent with the initial coding of a sample of the transcripts. As previously mentioned, these checks can be seen as an indicator of the trustworthiness of the analytic process, and as contributing to the validity of the conclusions drawn from the codes (Bazeley, 2007; Bazeley & Jackson, 2013; Rodham et al., 2015). The outcome of this phase was a collection of five master themes and 20 sub-themes, which are presented in the Chapter Six.

5.5.6 Phase six: Production of summary table and write-up. The analyses of data from the individual interviews and group discussions were combined. The final phase of analysis was the production of a summary table (see Table 3) and the write up of the themes and sub-themes identified from the analysis. The master themes and sub-themes were presented with direct quotes from the research participants, and is presented the following chapter.

Chapter 6: Results

Data analysis from data collection phase one and two combined identified five inter-related master themes and 20 sub-themes (see Table 3). This chapter will present the master themes and sub-themes with supporting extracts from participant interview transcripts. Extracts were carefully chosen because they present the most eloquent expression of each theme and sub-theme. This chapter serves to demonstrate a narrative interplay between the researched and the researcher.

Table 3

Master Theme and Sub-themes identified from the data analysis

<i>Master theme</i>	<i>Sub-theme</i>
1. Positive Change in Perspectives on Living	a. “Making the most of it [living with PD],” through re-evaluation and re-prioritisation b. “Finding meaning in caregiving,” through benefit finding and meaning-making c. “Touched by PD,” the desire to positively contribute to those affected by PD d. “We’re the lucky ones,” a sense of gratitude and appreciation through social comparison e. “Just got to accept it,” greater acceptance of the ambiguous nature of PD and life in general
2. Personal Growth	a. Improved interpersonal skills b. More knowledgeable c. More adaptable d. More capable e. Becoming emotionally stronger
3. Relationship Growth	a. Closer to person with PD b. Closer as a family
4. Contextual Experience	a. Meanings made about PD at time of diagnosis b. Person with PD’s experience c. Quality of pre-PD relationship with person with PD d. Support groups e. Past and/or concurrent adverse experiences f. Developmental stage of life and relationship
5. Lacking in Positive Changes and Growth-ful Development	a. No positive changes, only negatives b. “PD doesn’t interfere with our lives or relationship”

6.1 Master theme 1: Positive Changes in Perspectives on Living

This theme pertained to the positive changes that participants experienced in terms of their perspectives on living since their person with PD had been diagnosed with PD. When asked about the “highs of the caregiving experience” or, “whether there were any positive effects of PD,” many participants, like Katrina¹ (a 58-year-old woman whose husband was diagnosed 6 years ago) commented, “it [the PD diagnosis] changes the way you look at things [life in general].” In the wake of the presence of PD in their lives, these participants concurred that they had developed more of a positive attitude towards life, were better at focusing on the positive as opposed to the negative, and appreciated what they had rather than focusing on what they did not have. For example, Alex (a 58-year-old husband whose wife was diagnosed with Advanced PD [rapidly progressing] 3 years prior to current interview) said, “Yeah, and just enjoying [life] and being thankful for what we’ve actually got, what we can actually do, and do it.” Knowing the PD diagnosis and the possible negative impacts of the disease prompted each of these participants to positively re-evaluate their outlook and attitudes towards life in a positive sense.

6.1.1 Sub-theme 1a: “Making the most of it,” through re-evaluation and re-prioritisation. Numerous participants stated that the knowledge of the PD diagnosis, and the possible negative impacts that the disease would have on their lives forced them to re-evaluate their lives and what was important to them. For example, Alesha (a 66-year-old housewife, whose husband was diagnosed 7 years ago) reflected, “I guess you learn that some of the things that you thought were important in life are not anymore.” It appeared that for these participants, issues or concerns that may have upset them in the past were no longer important. These participants stated that they had re-prioritised relationships with significant others (including the person with PD, family and friends) and their own personal health as

¹ Each participant was given a pseudonym to preserve anonymity

being important, and concurred that they should not be taken for granted. For example, Colleen (a 50-year-old daughter who cared for her now deceased father who had PD, and currently for her mother who was diagnosed with PD 7 years ago) reported the presence of PD and the PD caregiving experience had put things into perspective for her, and furthermore served as a reminder about the preciousness of life and the importance of making the most of all aspects of life rather than delaying living:

To see what's important and I'm very much, well, I have come to the idea that, you know, it's people that are important. And it's time, you just can't put things off because you don't know that you'll be able to do them in the future because of health issues. But also too, you know, you can't go back and [you have to] decide, "yes I'll do that with Dad," because you don't know the nature of people's health, whether they'll be able to next week, next month, next year. So it has, sort of, altered my perception of, you know, what's important and just, you know, doing things. I think making the time to do things, you know, what's important and re-evaluating priorities. So it's the idea that, you know, people are important.

Like Colleen many of the participants reported that the restrictions and limitations imposed by the disease provided an impetus for making the most of their lives each day. For example, Alesha stated:

Make the best of each day and trying to fill your life with things you like to do, and trying to fit in and maybe do some things that you probably wouldn't have done, sort of trying to fit in everything while you're still fit enough to do it, they're good positive things [effects of PD].

Moreover when Alesha was asked, "What advice do you have for others in similar positions [PD participants]?" she responded:

Tap into and see what needs to change in your life, accept it and get in and enjoy yourself while you can. Do what you can when you can. A lot of people put off doing things until they're 65 or 70. Well that might be too late.

Following the PD diagnosis, these participants reported that they made substantial positive changes in their lives by restructuring their life-goals, and taking committed action towards doing what they valued, whilst the person with PD was still physically and cognitively able to do so. These changes included the participants choosing to spend more quality time with their persons with PD as well as their family, and bringing long-term goals forward. Long-term goals included overseas travel, relocation to be closer to their family and/or early retirement.

Some participants reported making positive changes to their lives immediately following diagnosis, typically during the latent phase of the disease. For example, Dena (a 55-year-old woman whose husband was diagnosed 15 years prior to time of current interview) reported, "we made decisions to travel while he was still able to. So it [PD diagnosis] changed us straight away, we thought if we are going to go together [sailing and travel], we have to do it now."

Other participants made changes during the manifest phase of the disease; in other words, when PD symptoms emerged, medication became less effective and decline in functioning was more apparent. For example, Martyn (a 32-year-old son, whose father had been diagnosed with PD for 13 years at the time of the research interview) stated that his father was initially reluctant to accept the PD diagnosis, and only began making lifestyle changes when he realised the extent to which the limitations and restrictions imposed by PD would have on his physical and cognitive functioning, and quality of life. Martyn reported:

When Dad [person with PD] finally found out that it [PD] was going to make such an impact on his life, I think it forced him to do the overseas trips (...) ² He has done a lot more than I think he would have.

All these participants believed this re-evaluation and re-prioritisation process resulted in positive outcomes. For example, Alex believed the mutual decision to bring his overseas sabbatical forward whilst his wife was still able to travel resulted in positive outcomes. Alex commented, “it [overseas sabbatical] eventuated in being one of the best times of her life since the diagnosis. It just got her mind off everything and we thoroughly enjoyed it. We had a fantastic time.”

Some participants reported that their attitude towards life had changed since providing care for their persons with PD, such as becoming more laid back, or easy going, and letting things go that they would have previously upset them. For example, Alex indicated that prior to his wife’s PD diagnosis, he had a tendency to control and plan all aspects of his life. But since the PD caregiving experience, it appeared that Alex was less preoccupied with the trivialities of life, and instead focused on filling his life with meaningful pursuits and interests. Alex commented:

I pick out the things that are going to value-add to your life, because you live your life for now and tomorrow and the near future, and you let the other things go by or you just park them and come back to them later or never. Just prioritize and pick things that are going to value-add to the here and now and quality of life. I was never like that before, I always used to be a super planner and control things, I’d plan for this and plan for that. But now I tend to sort of live for the day or the immediate future, and what Renee’s got to deal with. I was never like that before.

² See Appendix O for transcription conventions.

6.1.2 Sub-theme 1b: “Finding meaning in caregiving,” through benefit-finding and meaning-making. Some participants reported finding benefit or meaning in having their loved ones being diagnosed with PD and/or the PD caregiving situation. For example, Hannah (a 54-year-old wife, whose husband was diagnosed 16 years prior to the research interview) stated that the PD caregiving experience had provided her with a sense of purpose. Hannah reported that she had previously been grappling with a sense of meaninglessness and lack of purpose in life since taking leave from work as a nurse. She reported that she had taken leave due to a major depressive episode, which she perceived was associated with work-related burnout:

I guess there are [positive effects]. I mean, when I left work, I was a real mess. I had quite a major depression. So, in some ways, it's sort of, and I guess one of the big things was work. “What am I doing? Who am I, anymore?” I suppose one of the things that have come out of it is I actually do have a role, when people say what do you do, well “I am a carer.”

Hannah went on to describe that even though her nursing position had been overwhelming, she was able to make sense of the past adversity by seeing it as an opportunity to derive necessary skills that were serving her in the current caregiving experience:

The other things are that I do all the medical stuff, which makes sense because my background is medical. I am the one that does the research on the disease and the medications that are available. (...) The nursing background has been a real burn. I guess that has been a plus, because I didn't want anything to do with nursing or medicine or anything for quite some time. But actually I realise that having that medical background has helped me to understand what the doctors are talking about, and I am capable in the medical system and the hospitals in getting what Evan needs,

and being that support person, that interface for him, which I know he finds invaluable.

Martyn believed his career choice in nursing was influenced primarily by his mother's death, and his father's PD diagnosis:

I think probably the biggest impact it had was probably with Mum more so than Dad. In that, Mum was very, very dedicated, hands on. Because she had a very aggressive form of cancer. She was literally in hospital every day for, I can't remember how long it was now, but it was maybe three months or six months, along those lines, and I was getting more and more involved with her and interested in the medical profession, Because I was in finance, and I thought, wow, I would like to move in to radiography, or nursing. Just because I was so impressed with what I saw those people were doing with mum, and I thought that was amazing, and even I guess seeing what the neurologists and neurosurgeons can do with the technology, what they have been able to do with Dad [underwent Deep Brain Stimulation], I mean it has been amazing. I guess it is that side of it, and that's why I am actually at [name of University] now. I wanted to finally take up nursing.

Other participants made sense or positively reappraised (or reframed) the PD caregiving experience as, "a test from God" or, "a life lesson" or, "an opportunity to give back to persons with PD." James positively reappraised providing care for his wife as his calling in life:

One thing with this, is attitude, and I suppose I was always wondering, "what's God's will for me at this stage?" I think this is God's will. I see this as my vocation in life. If I treat it like that, rather than just something I've got to get through, it helps make it a little more meaningful.

These participants were seeking to make sense and/or ascribe positive meaning to past and current adverse experiences such as a past stressful work experience, the death of a loved one, or current PD caregiving experience. Moreover, it appeared that for these participants, constructing and ascribing subjectively satisfying meanings to the caring role appeared not only to be a strategy for making sense of difficulties and losses that accompany the PD journey, but also to be a way to find positive reasons to remain as a participant, and thus continue to be committed to the task of caregiving.

6.1.3 Sub-theme 1c: “We’re the lucky ones,” greater sense of gratitude through social comparison. Half of the participants perceived they were fortunate compared to others who were also affected by PD, or other health conditions (i.e., leukaemia). During their PD journey, these participants recalled meeting other persons with PD and their loved ones at PD support groups, research focus groups, and/or PD education sessions. They reported that they had compared their own personal circumstance with the circumstances of other persons with PD and their loved ones, and as a result concurred that they were better off than certain persons with PD and their loved ones that they had met. Consequently these participants stated that they felt a deeper sense of gratitude and appreciation for their own current personal circumstances. For example, Katrina stated, “along the way we have met many different people and heard many stories, and we come away really grateful, as there are many who are much worse off.”

These participants described many reasons for perceiving themselves to be more fortunate compared to others. Examples of some reasons for feeling better off included: their person with PD’s diagnosis could be worse (i.e., the diagnosis could have been a life threatening disease such as terminal cancer or leukaemia, as opposed to PD); their person with PD’s disease progression was slower or less advanced than other persons with PD they had met; their persons with PD had responded to medication better than other persons with

PD; their persons with PD had been awarded better treatment opportunities than other persons with PD; they were better off financially than other persons with PD and their loved ones; and they had better family support than other persons with PD and their loved ones.

For example Elizabeth (a 65-year-old retiree whose husband was formally diagnosed with PD 7 years prior to current interview) stated:

I mean we look around and say, “well thank God [it’s PD].” We’ve lost friends to cancer in a matter of a couple of years. (...) It’s [PD] not a death sentence. It’s not the awful something that’ll knock you off at the finish anyway.

Finally, some participants perceived that they were lucky because their persons with PD were easier to deal with than other persons with PD who they had met at support groups.

In Katrina’s extract, she reported that through comparing her personal situation with that of others (i.e., friends who were diagnosed with cancer), she recognised that not only could things be worse, but there were also many positives in her life. Seemingly maintaining this positive belief made her feel better about her own situation and ultimately led to a greater sense of gratitude or appreciation for her own life.

A number of participants acknowledged that there was a lot to be thankful for, and that the positives associated with dealing with PD outweighed the negative. These participants stated that they did not have much to complain about compared to others who were worse off (e.g., financially or health-wise). For example, Mary (a 68-year-old retiree, whose husband was diagnosed 7 years prior to the research interview) described how she was feeling depressed and downhearted about her PD caregiving situation, and concurrent and reoccurring stressful circumstance involving one of her adult children. Mary described depressive symptomology, such as finding it difficult to experience positive feelings. Consequently, she attended a general practitioner and gained a referral to a psychologist (at the time of the interview she had yet to attend). Mary described a sudden realisation that she

felt better. She attributed this to going through a “mental appreciation thought process,” whereby she compared her situation to a friend, who at the time was being treated for terminal cancer, and reminded herself that she had lots to be thankful for:

Recently I’ve been taking a friend in for radiation therapy once or twice a week, she’s got a roster of people to take her in and she’d had a mastectomy just before the radiation. 10 days after the mastectomy, I’m driving her to a job interview in town, and I thought, “you’re really going to have to get a grip because there’s nothing wrong with you, what have you got to complain about?” And that was on a [name of day] in this particular week, and the next [name of day] I was driving in to (name of suburb), we’re about an hour drive from [name of suburb], and it was an absolutely glorious day, the sun was shining, it was just beautiful and I was half way there when I suddenly realized that I felt fantastic, and I hadn’t done anything; nothing had happened to me to make that transition but I’ve actually been feeling quite good since then, and that was about six weeks ago. But I don’t know what happens, maybe it was just the mental process working through the fact that here’s my friend who had a mastectomy and is still going for a job interview, then I realised what we have to complain about actually and all the things we’ve got to be thankful for. And they far outweigh the negatives.

Some participants also reported a deeper sense of gratitude and appreciation for their own health, as a result of comparing their own health with their loved one with PD. Each participant reported that they were more aware of their own vulnerability to illness since the person with PD was diagnosed. They had a renewed appreciation for own their health and were not taking it for granted. For example, Dena reported:

I am frustrated with the whole thing [impacts of PD on their lives]. But I can't be more frustrated than Adam because he is the one who has it. It upsets me to see him

struggle. It upsets me that we don't have the same relationship as we did. But at the same time, I have to appreciate the fact that I am healthy and that I have a life.

Furthermore Colleen reported:

I suppose it's given me a great appreciation of, you know, how important your health is to you. And also too that, you know, you can't take things for granted, you know, how quickly things can change whether it's, you know, health—you know, others' circumstances. But then I think it goes back to age as well, because as we get older, we are more likely to have had people die unexpectedly in accidents or, you know, diagnosed of cancer or major illness or, you know, seen friends that have miscarried. So I suppose as you get older, you see more of life, more of a balance for putting things into perspective or context.

Consequently these participants made positive health-related behaviour changes (e.g., improved diet and partaking in regular exercise) since they had been providing care for their persons with PD. It appeared that a major motivation for making positive health-related behaviour changes was to increase the likelihood of remaining sufficiently healthy so these participants could continue to care for the person with PD for as long as possible. For instance, Carol (a 72-year-old retiree who has cared for her husband) reported:

I have to keep my health – to keep his health. That's basically it. And if I allow my health to go downhill then he'll go down too. Because he would not cope, he found it very hard when I had the heart attack.

Like Carol, two other participants expressed their anxiety and concerns about what would happen to their person with PD if they became unwell and could not continue to provide care.

6.1.4 Sub-theme 1d: “Touched by Parkinson’s,” the desire to positively contribute to those affected by PD. Several participants reported that since the presence of

PD in their lives, they had the desire to do something positive for the PD community. For example, David (a 58-year-old retiree whose wife was diagnosed with PD 3 years prior to this research interview) reported, “I mean, our family has been touched quite a bit with cancer, so I go on the relay for life [Cancer Council’s Relay for Life event] every year, I’ve done it for about nine years now and I suppose Parkinson’s is just another interest.” These participants became involved through the local Parkinson’s Associations (PA) via various means. Darren reported that he had been ‘heavily’ involved in the Parkinson’s community since his wife was diagnosed. He commented, “I wouldn’t have been involved if it wasn’t for Maggie being diagnosed with Parkinson’s. I wouldn’t be involved in Parkinson’s or the support groups (...) so I like to channel my efforts in that way.” Maggie was present at the time of the interview and also confirmed, “my husband has been touched by people with Parkinson’s and wants to give back something, to Parkinson’s, as a society” (Wife: person with PD). Darren likened himself to Clyde Campbell, the founder of the Shake It Up Foundation, and emphasised:

A bit like this guy [Clyde Campbell] who got involved up with the Shake It Up Foundation. This guy [Clyde Campbell] was diagnosed with Parkinson’s in 2004 or before, and happened to be a businessman, a successful one, and *very* wealthy. So he started the Shake It Up Foundation and donated five million dollars to Parkinson’s research ((unclear)). So he just threw himself in there ((inaudible)) Michael J. Fox Foundation, and now he is off around Australia trying to find a cure.

Seemingly for these participants, becoming actively involved in PD created meaning for their personal experience with PD, and helped them to find meaning (or purpose) in their own suffering or adversity in dealing with the disease. It appeared that the impetus for their involvement in PD associations or activities was altruistic. For example, Andie (a 57-year-old participant, who reported she had provided care for her husband for four and a half years,

following his PD diagnosis nine and a half years ago) expressed her willingness to be involved in PD research and was motivated by the hope of helping others with PD:

But at the same time it all needs to get out there, doesn't it? I mean, it is not going to help my man [husband]. I think I'm a lot more perceptive to what other people might be going through now, even though they might not have a person with Parkinson's, but they may be looking after a sick husband or something. I'm certainly more aware of others' carer roles, and what they might be going through. But it may help somebody down the road, and that is good. All this research and what not going on, well it is probably not going to help my man but, you know, we still plod along and join in and what not because it will help somebody else.

This motivator may be considered partially altruistic because there appeared to be rewards for the participant's involvement in the PD community and helping others. It appeared to provide further meaning for the experience they were going through or had gone through. Furthermore, it appeared to provide these participants with an opportunity to share knowledge and skills acquired through the caregiving experience, which in turn led to a sense of competence and mastery, and possibly a sense of usefulness and greater self-worth.

Darren explained his motivation for initiating and facilitating support groups was to share knowledge:

I'm still learning about how to support others. I am still on a long journey. Anything I learn [about PD and dealing with it], if I can pass that on to people, I do (...) that's basically where my involvement with the support groups comes from.

For some like Noel (a 68-year-old retired academic, whose wife was formally diagnosed with PD 15 years prior to the current interview), through doing something for others such as conducting his own research on the aftermath of Deep Brain Stimulation (DBS) surgery, appeared to help him make sense of his caregiving experience. A prominent

theme at Noel's interview (and for others, like Terry, Dena and Zara) was dealing with the aftermath of this surgery. It is possible that conducting research was cathartic, a way of regaining control to combat a sense of loss of control, powerlessness and uncertainty that both Noel and his wife experienced pre and post-surgery:

We were rattled by unexpected events that happened after the procedure. So we are doing research, a longitudinal study of people who have had the DBS, and we are going to publish something on this, and part of that story. And one of the core features of this study was interviewing the carers, as well as the people who have participated in this study. Because the carers' perspective of what's happening, because they observe things that their partner does not always observe. And they are not privy to the information that the neurologist has given the patient.

Finally, it appeared that another motivator for getting involved in PD was to raise awareness of PD. Several participants expressed that the general ignorance about PD was profound. David reported one of his primary objectives was to raise public awareness for PD. He believed the general public were largely unaware of PD, unlike cancer. He reported cancer fund raising attracts substantially more attention than PD:

The main goal, I suppose with anything is trying to get more awareness out to what your problem is (...) And again because it's not life threatening, like cancer is, we feel that there isn't research, well there's not that much general knowledge of the condition [PD]. This Sunday we're going on the Parkinson's walk around [name of city] and that's the third year.

A number of participants reported that their friends, family and the general population had nil or limited awareness or understanding of PD, and as a result did not know how to treat their person with PD. These participants grappled with social incidences whereby a person with PD was accused of being "a drunk" or an "idiot" because of the physical

limitations imposed by the disease, manifestations of the tremor and slowness in speech.

Terry (a 68-year-old retired husband, whose wife, Penny, was diagnosed 18 years prior to the current focus group discussion) reported that those who are unaware that his wife had PD become impatient with her:

Other people who don't know her, don't know she has Parkinson's and don't know how, and are less willing to help. I still keep saying we should have this card that says "I have Parkinson's, just have a little patience." Once people know Penny then she is okay. But I think the people that don't know Penny, it's hard for them. (F1: Husband)

Perhaps for each participant these negative experiences motivated them to raise awareness, with the view to protecting and helping the person with PD. To promote understanding and knowledge of the disease, in the hope that others would know how to better treat the person with PD. This may ultimately contribute to the person with PD feeling more understood, and less marginalised and ostracised in society.

6.1.5 Sub-theme 1e: "Just got to accept it," greater acceptance of the ambiguous nature of the PD and life in general. Several participants acknowledged that acceptance was important in dealing with the uncertainty and loss that often accompanies an incurable and progressive disease. As Robert (a 73-year-old farmer, whose wife had been diagnosed with PD for 1 year), highlighted, "I think number one is acceptance. I accepted she had Parkinson's." These participants commented to the effect that they had no choice but to come to accept PD and its impacts because there was nothing they could do to change the incurable disease. For example, Mary (a 58-year-old retiree whose husband was diagnosed 7 years prior to the research interview) commented:

I think it's just something that you have to accept, there's nothing you can do about it, at this stage there is no wonderful cure and as far as both of us are concerned he can

just make the most of what abilities he's got, and live within those capabilities with his work and that.

For Mary and many other participants, acceptance was expressed through stoic statements that were common in the participants' accounts pertaining to acceptance, such as "it is what it is" and, "it's the cards we've been dealt." Another example is that of Shelley (a 49-year-old finance officer who provides care for her father, who was formally diagnosed with PD 5 years prior to the research interview):

I- I just accept it as, you know, this is my lot in life I guess. This, it is not ideal, it is certainly far from perfect but it is certainly not as, I don't know, I guess I don't dwell on it too much, there are times when I think, "oh I wish I could remove myself away from it," I mean I guess at times I do that. I have learnt to do that but I guess I don't dwell on it, you know, I just get on with it and just do it.

Many participants described multiple losses throughout the caregiving journey, that they were forced to accept. They were initially required to accept that there was something wrong with the person with PD, and then required to accept the diagnosis of a debilitating, irreversible and incurable disease. Subsequently, as the disease progresses they are forced to accept their loved one will never be the same again and will come to depend on them for assistance with daily living, and they will be required to assume the role of a primary caregiver.

However, it was apparent across the data that there were varying levels of acceptance between the participants, and varying levels of acceptance in their own personal PD caregiving experience. Acceptance or lack thereof (i.e., denial or avoidance) was discussed at varying stages of the PD experience. In some participants' accounts pertaining to acceptance, there emerged a continuum between acceptance and avoidance coping. For

example, Rosemary described herself as being in denial when she commented, “being a bit of an ostrich, wanting to bury my head in the sand and not think about, and let it spoil today.”

Some older participants readily assumed the caregiving role, whereas others, like Dena, struggled to come to terms with the prospect that their loved one with PD would come to depend upon them, and they would have to assume the role or identity of a carer. Dena concurred that she was in denial about having to become her husband’s carer:

I understand that you have to have carers. I mean, I am in denial but if I ever had to care for Andrew (husband, person with PD). I’m sure I’m in denial, but that is how it is. I don’t know that we have even accepted Parkinson’s to be honest with you, probably a little more so now than what we did five years ago. But, you know, I don’t think about the fact that I will have to look after Andrew and care, you know, help him shower and, I don’t even think about that. And I don’t think he does either you know. Um, so we probably will have to one day but we don’t think about it. Maybe there will be a cure, well he lives in hope there will be a cure for Parkinson’s, and I just don’t think about it.

The participants who had been providing care for many years described a gradual acceptance for the losses imposed by PD. As Noel (who at the time of the interview perceived his wife had experienced a substantial decline in functioning as a result of disease progression in the months leading up to the research focus group) reflected:

That’s the nature of the beast. There is this awful road that we are on, and there is no deviation from it. It continues in one direction. I guess there is a mental acceptance that you have to make, and I guess it took me a long time to get my head around that to be honest.

Some participants stated that the PD caregiving situation had taught them to become better at accepting things in their life that cannot be changed (e.g., progression of the

incurable disease) and to focus on the things they could change (e.g., improving quality of life). For example, Alex described this coping mechanism as a *defacto cure*:

I think my nature and maybe my career [dentist], I think maybe it's sort of a defacto cure. I'm almost controlled by assisting her and improving quality of life. I know she can't be cured, that just sort of pharmacologically managing a progressive disease, and that's all we can do. There is no cure. But by me keeping her safe and doing all these little things which prevent infection and prevent falls and keeping her nutrition up and whatever, you think in place of a cure this is it, because we can't find a cure. So you feel probably a satisfaction that she's comfortable and her quality of life is as good as can be, as good as I can do, you have a sense where you feel comfortable with that but achieving that – or getting to that point.

Accepting the ambiguous nature of the disease and life was more apparent in those participants who were further along in the journey, and/or those who had previously experienced trauma or adversity in the past (or concurrent to caregiving), or more so for the bereaved loved ones that had provided care. They had become better at accepting things in their life that couldn't be controlled such as the ambiguities of life (e.g., being diagnosed with PD, the personal diagnosis of breast cancer, and the death of loved ones), and to focus on the things they could change (e.g., developing a positive attitude and making the most of life in the face of such events).

For example, Florence (a widow and retired nurse whose husband died 5 years prior to the current research interview, who provided care for her husband for approximately 14 years) recalled witnessing her grandfather's ill health during her childhood, which shaped her decision to become a nurse. Florence also stated that prior to providing care for her husband, she also cared for her mother who eventually died of bowel cancer. Florence believed that as

a result of her professional and informal caregiving experiences she had becoming more accepting of existential issues, such as the finiteness of life. She reflected:

It hurts but can't save them ((sighs)). I've had to come to terms with the fact that everyone, no matter who we are, and what we do, we all go through that stage, and we all ... we are all born, and in the end, we will all pass away.

6.2 Master theme 2: Personal Growth

This theme related to ways in which the participants perceived that they had intrinsically grown as a person as a result of their PD experience. The vast majority of participants described at least one facet pertaining to personal growth since the presence of PD in their lives.

6.2.1 Sub-theme 2a: Improved interpersonal skills. A number of participants reported that through the PD caregiving experience they had either derived new interpersonal skills or improved upon pre-existing skills. Five facets (or examples of interpersonal skills) pertaining to this sub-theme were derived from the transcripts: patience; empathy and compassion; interpersonal sensitivity and respect; listening skills; and assertiveness.

Patience. Many participants reported learning to become more patient as a result of providing care for their persons with PD. For example, Daisy (a 68-year-old participant whose husband had been formally diagnosed for 21 years) noted:

I've had to learn to be more patient, and sometimes I struggle with that. I know that he can't help being slow sometimes, and then I feel a bit, "well hurry up" but then I don't like myself very much [laughs] for feeling like that. (P17: Wife)

Many participants concurred that developing patience was essential in PD caregiving as the persons with PD often took more time to do daily activities. Although some stated that they recognised that this slowness was out of their person with PD's control, many participants struggled with losing their patience and managing their own feelings of

frustration that came with watching their loved one take inordinate amounts of time to complete the most basic tasks. The participants who had a tendency to lose their patience learned to adopt coping strategies (i.e., taking a step back, looking away, focusing on something else) in an attempt to be more patient, because it appeared that they recognised the negative consequences that losing their patience had on the person with PD. As Elizabeth stated, she coped with her feelings of frustration and loss of patience by walking away and leaving her husband to attend to tasks (e.g., dressing) on his own in his own time. She acknowledged that if she does things for her husband it robs him of his independence:

John's slowness in doing things but as long as I'm not watching it doesn't matter.

You know [laughing]. You know if you're watching someone you want to take over and do it, but you can't do that. Because you're going to take away their independence (...) so I just leave him to it. And I don't care how long it takes as long as I'm not watching, because you get impatient when you're watching someone doing things slowly. And we just allow ourselves time so that doesn't happen, you know?

A few participants attributed the difficulties with loss of patience to their predisposed personality characteristics. These participants described themselves as being hot-headed, impatient, orderly, organised, and/or a bent for "getting things done." For example, Susan (a 68-year-old retired teacher, whose husband had been diagnosed for 11 years) stated:

I am an ordered person and I like to be organised. So the challenge for me is not jumping in, and not assuming that what I have got in my mind needs to be done now.

That it's not going to be done now. It is going to take longer. So adding time, and making allowances for that to happen, and then not losing my patience if something that doesn't go the way up here [pointing to head] says it should, sort of thing. ... Just not jumping in. It's pretty hard sometimes (...) so I try not to jump in so much now.

But sometimes, there is a little demon inside that does it anyway (...) it's the

patience thing for me (...). I am a list person, I have to have lists of what I am doing, I have to get it done in this order, and tick it off, with that impatience to get it done to a timeframe that I feel is right, I really send him off the rails sometimes, when he can't think and he gets anxious, and can't cope, so for me, it's cutting back, and holding off and watching what you say and how you say it so you are not throwing his life into more chaos. But yeah, for me it's just having that patience, don't jump in or do something or say something that is going to just confuse his mind and he can't process the thoughts, and make him do the things that I want him to do. (F2: Susan)

Empathy and Compassion. A few participants reported that they had become more empathetic and compassionate as a result of PD caregiving. Darren perceived that he had become more empathetic and compassionate, and ultimately a “better person” through the PD experience:

To be frank I probably wasn't a particularly caring person (...) I had a lot of qualities that possibly weren't very nice or very pleasant. So I certainly wasn't an angel, or someone that had, you know, very good qualities. But it [PD] determines that you have to adjust (...) certainly think I am a better person than I was (...) I have probably developed in looking after another person, rather than myself ((inaudible)). Well, it's brought us closer together. You need to think of someone, other than yourself in more detail, you might say more compassionate, I would have said I'm more empathetic, it's putting yourself in another person's shoes, sort of thing. It seems you think about yourself less. (P1: Husband)

Some of the participants reported that they had taken more of an interest in their person with PD, and were putting the person with PD needs above their own. For example, Dena reported, “I have focused more on him now, in the past I think I was quite a selfish

person and focused on myself” (P3: Wife). Another participant, Alesha, described herself as “not a natural carer,” and perceived that she struggled with many aspects of providing care for her husband. Alesha reported that through her PD caregiving experience she had become more empathetic and compassionate for others also in the PD caregiving situation:

I’m a lot more perceptive to what other people might be going through now, even though they might not have a person with Parkinson’s, but they may be looking after a sick husband or something, I’m certainly more aware of others carer roles, and what they might be going through. (P25: Wife)

Some participants acknowledged that empathy was a desirable personal characteristic or strength for PD caregiving. Zara reported, “patience, energy, understanding of the actual disease, and empathy for the people who are struggling with it. I think that if you can talk to others who have gone through it, it is also a great help” (P2: Wife). Five participants described themselves as having a compassionate nature. Some concurred that having a caring nature or previous experience in either professional (e.g., nursing) or informal caregiving was desirable, and had assisted positive adjustment during their caregiving experience.

Interpersonal sensitivity and respect. Several participants reported that they had become or were becoming more cognisant and sensitive of their persons with PD’s existential needs and concerns (e.g., independence, significance and meaning), and in turn became better or were becoming better at respecting their person with PD’s personal boundaries. During the caregiving situation, these participants had become more mindful of maintaining their person with PD’s independence and were cautious of trying not to interfere with or take too much responsibility away from their person with PD unnecessarily. These participants stated that it was important for their person with PD to maintain their own life, within their physical capabilities, in order to uphold a sense of positive regard and self-esteem as well as to continue to have a sense of purpose. Darren’s extract illustrates this, and

his wife, Maggie (person with PD, who was present at the interview), also contributed to the discussion:

“I try not to take too much responsibility from Maggie, because it is important that she looks after herself. So it’s important that you are there when you are needed, but you do not want to interfere with the other person’s life//³” (Darren)

“Yes”// (Interviewer)

“They are *people* [person with PD], who need to look after themselves.” (Maggie)

“That’s true”// (Darren)

“But you don’t want to take their independence from them, as they need something to do. To ... fulfil their day.” (Maggie)

“But the vast majority of people with Parkinson’s, they need to be able to manage what they are going through, and to manage their lives for themselves. So if there is something that they *can’t* do then, they need to find something they can do, and find something else for them to do.” (Darren)

“To have a sense of independence and a sense of meaning, in their own life?”

(Interviewer)

“Yes you need to have something to do for the day when you wake up in the morning.” (Maggie)

Another participant, Terry, recalled that after his wife, Penny, underwent surgery for her symptoms, her physical capabilities improved. Consequently, Penny was keen to resume pre-existing role responsibilities (e.g., cooking) that were seemingly integral to her self-esteem:

³ Note: // = Double oblique indicates a point at which a current speaker’s talk is overlapped by another (see Appendix O for transcript conventions).

I have found that lately with Penny and the cooking. I mean, I do all the cooking, but I can see that she's sort of wanting to come back into part of the cooking. So you have got to stand back and come in and do her little bits. And she seems to be more contented if she has contributed to the meal or done something. It seems to make her feel a lot better. (F1: Husband)

In Terry's account, he demonstrates awareness of his wife's need for autonomy, independence, responsibility, to have the freedom to choose her own actions and to have a sense of purpose; seemingly, all of which were integral to her sense of self and self-esteem. A common problem was finding a balance of how much help to provide the person with PD without crossing their personal boundaries and ultimately disempowering the person with PD. Many participants reported that they were getting better at achieving a between providing minimal support to their person with PD, whilst maximising their person with PD's independence and autonomy. Many participants realised when they had not respected their loved one's personal boundaries because that person would get upset. An example was provided by Paul (a 58-year-old teacher, whose wife was diagnosed four years ago):

I try to take as much as I can off (name of wife, person with PD) to ease any sort of stress, which sometimes leads to a sense of frustration on her part. And [I get] a feeling that she doesn't want everything taken off her, that she is capable of doing some stuff. [Paul imitates his wife] "Well, I don't need you to do those things for me." And we've had those discussions where she tells me that I am too bossy and that I boss her around and everything. And I say, "I don't boss you around. I just give suggestions, and say [giggling] why don't you go and have a sleep?" and she'll say, "I don't want to have a sleep. Stop telling me what to do." (P12: Paul)

Terry described how his wife Penny withdraws when he tries to help her out in social interactions: "It's when you jump in, or when others jump in when you can see that she just

backs off and gets quieter and quieter.” Similarly, many participants described that trying to help or provide support for their person with PD, it appeared to have a negative (rather than positive) impact on the person with PD. In these instances their person with PD had expressed that they felt controlled, bossed around, nagged or treated like a child by the loved one providing care. Susan reported:

I think I have had the same experience with Terry [another attendee at focus group], like, [Susan imitates her husband] “don’t take that away from me” or, “you’re bossing me around” or, “you’re organising me.” I didn’t see it as that, but obviously I was. It’s just trying to find a common ground where you can work together.

Another participant reported:

My way of caring is a nagging way of caring, which I’m always getting told off for. (...) My husband [person with PD] is not really good at organising himself, but then when you try to organise him he goes crook [gets upset].

Many participants described interpersonal tension and conflict during the loved-one-to-carer transition when the loved one took more of a carer role, and assumed the role responsibilities (e.g., household tasks, driving and so forth) that formerly belonged to the person with PD, which in many cases, resulted in the person with PD feeling disempowered or undermined. For example, Noel stated:

I think in the last year or so, there has been a growing acceptance, from Shelia [wife, person with PD] that she can’t do the things that she would like, like she used to do. But prior to that there was a constant tension about wanting to do something, it [a task] would be started, but it would never be finished within any time scale of value to humankind. So now we are going through a transition period, where I have taken on more and more of the housework and the cleaning. I do the ironing, I do the washing, I do most of the cooking. I am one of the.... I am guilty of Terry’s [another

focus group attendee, PD participant] transgression, in that I get so frustrated in waiting for things to happen, and they don't, so I do them myself. And that sort of shuts out Shelia [wife, person with PD] from doing it. And I know that it's wrong, but it's the way I cope to do it that way, but it's the way. She is much more reconciled to that now than she used to be. She used to get very annoyed. She described it as taking things away from her ((clears throat, voice breaking)). And in a sense I was. But I just couldn't help myself. I guess it was just my personality, superimposed in a sense. I am an ordered person. I like order. I like neatness. And that is not what happens if it is left to my wife.

Noel revisited this issue later on in the focus group:

She would want to do things herself, and this was two to three years ago, and she would resent the fact that I was taking stuff away from her, and I was thinking that I was helping by doing it. So for many years that was a source of tension, but now I see my every assistance, was seen as taking something away from her. (F3: Husband)

These participants reported that they had learned from their mistakes, and provided examples that demonstrated they had become better at respecting the person with PD's internal personal boundaries. Hannah demonstrated her awareness of the sensitivities involved with the changing role responsibilities when taking over more of the decision-making, compared to pre-PD, when they used to make decisions together. Hannah acknowledged, whenever possible, that she needed to involve her husband in the decision-making process during times when he was functioning better. Hannah believed by continuing to include her husband in decision making, this helped him to feel capable of making a contribution, seemingly integral to his self-worth. Hannah reported:

I feel I am making all of those decisions ... I've actually learned with that, that I need to be really careful ... to talk to him at a time when he is actually able to talk to

me about it. Because, as you know, there are parts of the day when he can't concentrate enough on that's sort of things to actually to be able to think it through and make a decision. The decision-making, that was a very hard thing. We had always talked about things together and decided on things together. And certainly before the surgery [Deep Brain Stimulation], Evan couldn't make a decision about anything. The symptoms were just so distracting. That was a very, very difficult at those times.

Listening Skills. A few participants reported improved listening skills, which they perceived to be a result of PD caregiving. These participants concurred that it was because of two reasons: firstly, the person with PD had speech problems (e.g., soft voice, monotone), and secondly, the person with PD had difficulty expressing themselves because of the physical and cognitive impairments associated with the disease. At the interview with Darren, his wife, Maggie, said that she thought Darren's listening skills had improved since he had been providing care for her.

"I've become more patient." (Darren)

"More of a listener!" (Maggie)

"More of a listener, yes. See what happens here's a good example. Because I'm deaf ((laughing)), and I am in the office at home, if Maggie calls out, or she may say something. And in the past, when I couldn't hear properly I would have thought, 'I can't hear, so I won't worry about it.' But now, if I hear she is saying something I will get up out of the office, and find out if she wants something. Because it could be that she is in a difficult situation or something like that. So those are the things that change too, the situation changes, so you have to change too. And I think it will become more difficult, because Maggie, well, for people with Parkinson's it becomes

much harder for people to express themselves clearly. So you have to have a lot of patience, to find out exactly what kind of care they want.” (Darren).

In this extract, Darren illustrates that listening, paying attention and patience are important skills to have when providing care for persons with PD because PD often impairs the speech of those affected. Several participants agreed that listening skills were considered a desirable personal characteristic or strength. A couple of participants believed they already had good listening skills and perceived that this stood them in good stead in the caregiving situation. Whereas other participants like Alesha struggled with listening and believed that continued improvement was warranted:

And trying to listen, he always tells me I’m not a very good listener but he tends to repeat himself a lot of the time, but trying to learn to respond, to be more responsive and say well you know, I don’t know what you would say when he keeps repeating himself ... maybe not trying to make him feel---

Assertiveness. Two participants reported that they had become more assertive in their interaction with others since providing care for the person with PD. In both instances this appeared to be motivated by getting the best treatment for the person with PD. One participant, Hannah, felt she had become more assertive because of her husband’s decline in interpersonal functioning. Hannah, like many loved ones, stated that others begin to ignore the person with PD and instead talk to the loved one. In Hannah’s case this prompted her to be more assertive in directing the conversation towards her husband in an effort to include him and maintain his self-esteem:

I think one of the other things that aggrieve me more than anything is these people, because Evan is often quiet or doesn’t say much, people either treat him as if he is invisible ... or that he must be stupid. That the Parkinson’s has made him stupid and that makes me quite angry. They just bypass him ((voice breaks)). Even sometimes

good friends, maybe there are just thinking that they are being very kind about not drawing attention to the fact that he's not able to speak clearly or. ... And particularly when I can see he is actually trying to say something. I guess I have got a lot more assertive. That may be one of the things that has come out of it. In a nice way, like if we're out and having a conversation and I can see that Evan wants to say something, I say, "what did you want to say love?" and it's loud enough that everyone says, yes Evan. Because it hadn't occurred to them, the fact that he is actually sitting there with a bright mind, wanting to contribute. But it's just going to take him a lot longer to get the words out. Or you know, he has to have them actually listening before they can hear him trying to speak. Yes, so that is a bonus, and of some help to him as well.

Colleen provided another example of becoming more assertive in terms of liaising with health professionals and administration staff, in order to get the best possible care for her father:

And I think because I'm sort of a person who likes to find out information, you know, the nitty gritty of the medical details with Parkinson's and, you know, how I used that example [provided earlier on at the research interview] of being able to make a subsequent appointment on the day of the appointment rather than getting a letter in the mail and at the time it may or may not be suitable? I mean I am able to do that sort of thing, but also I find it makes it easier having that [personal] quality available to, you know, to get information and I've learned to be assertive.

6.2.2 Sub-theme 2b: More knowledgeable. Many participants shared ways in which they had become more knowledgeable since the presence of PD in their lives, which included developing a better understanding about the nature of PD and increased self-knowledge.

The majority of participants stated that they had nil to limited understanding and knowledge about PD at the beginning of their PD journey. Many stated that they had no experience with PD because they did not know anyone with the disease before their love one was diagnosed. Many stated that they did not know what to expect of PD and the implications for their future, specifically in relation to the disease trajectory and the impacts PD would have on their lives. For example, Martyn recalled the time of his father's diagnosis, "we [his family] didn't know basically what Parkinson's disease was. Well, I definitely had no idea what Parkinson's was." One participant described a steep learning curve in terms of acquiring knowledge about PD since his wife was diagnosed with PD.

It was apparent in the accounts of a vast majority of participants that they had acquired a deeper and broader knowledge and understanding about the disease over the course of the PD journey. Acquiring knowledge appeared to be a coping strategy to deal with the uncertainty associated with the nature of the disease. At the time of diagnosis, the majority of participants stated that they were determined to find out as much as possible about the nature of the disease and possible treatments. They began to research the disease either by contacting their local Parkinson's Associations; joining a support group; engaging in their own research on the internet through reading online articles, journals, and books; and attending seminars and conferences. For many participants, research began immediately after receiving the diagnosis – during the latent phase of the disease – when the person with PD's symptoms were asymptomatic, concealable or at least not overtly disruptive to life. For example, Susan reported:

Well, I am a person who likes to know what to expect. I was on the phone to Parkinson's Queensland to get information, it wasn't like we are going to beat this, we are going to fix this, I like to know what to expect down the track.

For other participants, research began during the manifest stage when symptoms began to impact the quality of lives for both the person with PD and the participant. It appeared that acquiring knowledge and keeping up-to-date with advancements in research was primarily motivated to alleviate anxiety, and for participants to regain a sense of control over an incurable disease typified by uncontrollability. Keeping abreast with research advancements pertaining to treatments and finding a cure for PD brought many participants hope and optimism for the future. David stated:

I suppose you can't, I think I'd be more concerned if she [person with PD] was diagnosed with cancer and said the prognosis is two or three years. So at least with this, with the way medication is and also with the huge advances in research over the last five years there will be huge advances in research over the next five to ten years. ... So we focus on that, we say well there is research.

Although many participants were realistic that a cure would not be discovered in time to help their person with PD, the research instilled hope. Five participants believed that a sound knowledge and understanding of the disease was of benefit in the PD caregiving situation and seemingly assisted in positive adjustment to the challenges presented as the disease progresses.

In terms of self-knowledge, some participants stated that the PD caregiving experience provided an opportunity to develop better self-awareness. These participants reported that by attending to daily caregiving tasks, they gained insight into their personal strengths and weaknesses through a process of solitary self-reflection. For example, Alesha reported:

I was a fairly strong character anyway but it [PD caregiving] certainly helped me to be much more determined and much more willing to persevere and I'm definitely learning things that I didn't know before. You do learn things about yourself, and you

also learn things, how can I say? I'm getting to see what I may be like and maybe I could be like, I have to struggle with when I get really down and a bit depressed I have to really look at what am I really depressed about- I have to analysis things to see what is really the cause so that I can deal with that real cause.

Alesha went on to say that the PD caregiving situation had taught her to ask for help, which also demonstrates becoming more assertive, as opposed to being passive aggressive (e.g., complaining and whining):

I think because of my strong character, I probably would not be inclined to ask people for help but now I am aware that I won't be able to do everything and so now I'm more willing to ask for help when I need it, and that's particularly with the family. I've always had this philosophy that we shouldn't bother the kids, they've got their own lives and their own families to be worrying about, they shouldn't be worrying about us so we've involved the children a lot more, in the last two years probably. (...) I'm getting them to take a more active role now in those kind of things, because when I used to complain about things they never really used to know what I was talking about when I'm having a bit of my whinge and grizzle. But now they actually know what I'm talking about [when asking for help] and sometimes they can offer me some helpful advice. (...) I think that was my self-awareness realizing that I would not be able to do this caring job all on my own, and a couple of the children started saying, because I think a couple of times when I got really down, one of them in particular came along and said, "You've always been there for us mum and you've always helped us out of---" because one of my daughters had postnatal depression and she said, "Mum you were always there for me and helped me out of my hard times, when I was down in the pit, we need to be able to be doing this for you now, we need you to tell us when you need our help" because they didn't know what they

should be doing. I've had time to think about that and I thought, "Yeah, maybe we should be involving them more," so I guess it was sort of me becoming aware that I'm not going to be able to do all this, that I will need their help if we're going to see this journey through.

Two participants perceived that attending a psychologist during their caregiving experience facilitated improved self-knowledge and highlighted areas of personal weakness (e.g., uncomfortable about asking for help), which appeared to serve as a catalyst for positive change and growth (e.g., being more assertive of needs and asking for help). For example, Katrina reported:

I did a lot of soul searching and the thing for me was asking for help. I didn't think that I would be able to do that. And going to see a psychologist (....). The straw that broke the camel's back was probably the Parkinson's, um, and yes and yes I just had to go and do it and I am happy I did, but it took courage to go (....). It [attending counselling] helped me to adjust, and that there is help out there. But the first point of call has to be yourself. When you are able to help yourself, you have to be able to help yourself. You can help others along the way, but the inner strength has to come from you. But nobody else can get you to that point.

6.2.3 Sub-theme 2c: More Adaptable. Nineteen participants reported improved adaptability and flexibility as a result of the caregiving situation. These participants believed these improved skills/abilities were due to adjusting to the unpredictable nature of PD as well as symptom fluctuations. A number of participants stated that every day was different and as a result, they had to adapt to the constantly changing caregiving situation. Participants reported that they were required to constantly adapt the level of care they provided depending on the person with PD's symptoms and functionality at any given time. Hannah emphasised the unpredictable nature of the disease, "our day-to-day life, well it varies, like anybody's

with Parkinson's. It depends on how he is, not just each day but through the day, minute-to-minute or hour-to-hour." Hannah is describing symptom fluctuations associated with the effects of medication – that is the *on* and *off* periods.

Several participants reported that they coped with the constantly changing caregiving situation by taking it one day at a time. Furthermore, they tried to make the most of the times when the medication was working and the persons with PD had improved functionality, as well as being flexible and changing their plans depending on their persons with PD's capabilities. For example, Alesha stated that she tried to live day-by-day without worrying about the future. She conceded that this was not easy for her to achieve, however, she tried to do so regardless. Alesha reported:

I guess I have learnt, this is on the whole because I don't always put this into practice, but I always come back to it, it's always my rock if you like to say. I'm learning to try and live one day at a time, instead of looking to the future. And I'm doing that with God, because, I think for me my stress is when things get on top of me, I race ahead and I'm looking at this and that, and how am I going to get that done. So getting back to basics, and just trying to live one day at a time, and getting the best out of my day is probably the thing that I've learnt more than anything else. (...) I think now, that if he's having a bad day today doesn't necessarily mean he's going to have a bad day tomorrow.

Darren believed that through previously running his own restaurant, he learned to be adaptable. He concurred that this transferrable skill was of assistance in the PD caregiving situation:

You have to have the ability to plan, and to face day-to-day circumstances
((inaudible)). You have to have the ability to scrap plans that don't eventuate because

she's having a bad day, and not functioning well (...) I had to take to day-to-day planning more, because I don't know what circumstances I may face.

As illustrated in a previously presented extract, Alex described developing more of an easy-going and less controlling attitude. Alex indicated that prior to his wife's PD diagnosis, he had a tendency to control and plan all aspects of his life. But since the PD caregiving experience, he was more accepting of the things he could not control (e.g., the progression of an incurable disease), and rather focused on the things he perceived he could control (e.g., partaking in activities that added value to their lives, and making the most of each day):

I always used to be a super planner and control things; I'd plan for this and plan for that. But now I tend to sort of live for the day or the immediate future, and what Renee's got to deal with. I was never like that before.

6.2.4 Sub-theme 2d: More capable. Some participants reported that they felt more capable since providing care for the person with PD. These participants reported that they were required to assume role-responsibilities (e.g., performing tasks such as maintenance, book-keeping, cooking) previously performed by the person with PD because of the decline in that person's physical and cognitive functioning associated with the disease. These participants described a sense of mastery and achievement from performing tasks they previously did not perceive he or she was capable of prior to the caregiving situation. As a result they described a greater sense of self-sufficiency. Some participants felt more confident to try new and unfamiliar things. Two bereaved participants provided examples of personal growth pertaining to this sub-theme. Florence recalled that during the end stage of her husband's life she was no longer able to care for him. Consequently, he went to a nursing home. In her husband's absence, Florence perceived that she had learned to perform role responsibilities (e.g., driving and maintenance tasks around the home) previously assumed by

her husband. She described feeling more confident in her abilities as a result of learning new skills associated with performing these role responsibilities:

When Harry went into the nursing home, I came out of my little comfort zone that I had to do things for myself, by myself. If I wanted to do something or something went haywire at home or that screw or that needed changing or I had to mow the grass and Harry wasn't around to tell me off for doing the wrong thing, so to speak, so I learned to do it. So just it's probably how I have grown in the last four years (...) all the driving I had to do. He gave up his license when Harry turned 60, he gave up his license and I just had to take over all the driving so I had to concentrate on all of that and to make sure that the vehicle was okay; because usually Harry did all that. I had to learn all those things.

The other bereaved participant, Patricia (whose husband passed away approximately seven years prior to the date of the current research interview) also believed that she had performed tasks during and after her caregiving experience that she would not have thought possible:

I did things [whilst providing care for her husband] that I'd never ever—if you'd have told me 25 to 30 years ago that I would have done what I did, I would not have believed you. I definitely wouldn't have done. But it's amazing what you'll do when you see the need there and you improvise with things. You have to be the person running the house, you have to be the person doing the gardening, you have to be the person doing everything. And we did everything together for a number of years. But, oh yes, definitely. You just—35 years ago if you'd told me what I did or what I was going to do I just would have just laughed at you ((chuckles)). There's no way.

For these bereaved participants the PD caregiving situation provided an opportunity for them to realise that they possessed capabilities and strengths that they had not previously

recognised. Consequently, PD caregiving made them feel stronger and better equipped to handle situations, which in turn appeared to bolster self-esteem. As Florence emphasised, “that’s definitely what’s come from all of this [PD caregiving]. It’s made me a stronger person, a more self-sufficient person.”

6.2.5 Sub-theme 2e: Becoming emotionally stronger. Several participants reported that the PD caregiving experience had made them emotionally stronger. For these participants it seemed the perception that they had successfully negotiated challenging times during the caregiving situation, resulted in appraisals such as growing stronger or becoming more resilient. For example, Patricia reported, “I think you become stronger people, a stronger person, you don’t become—I’m not as timid about doing new things now as I used to be. I feel a stronger person.” Florence, another bereaved caregiver like Patricia, reported that:

I had to go through this sickness [husband having PD] and all these sort of things, I feel that this is what my life is about, being given these challenges, and I am being challenged to rise through it. And it’s going to make me strong for whatever else is thrown at me, sort of things.

Another participant, Libby (a 32-year-old researcher, who had become the primary caregiver for her father with PD after her mother died of cancer several years ago) reported: “I’ve found over the years that I’ve got this strength from somewhere, I don’t know, it just feels like an inner strength that I can call upon when I need to, when Dad’s not so good or whatever.”

6.3 Master theme 3: Relationship Growth

This theme pertained to the positive impacts PD had on the participants’ relationships with not only their persons with PD, but other family members and friends. A considerable number of participants experienced strengthened relationships since the presence of PD in

their lives. Two sub-themes pertaining to Relationship Growth were identified: 3a) Closer to person with PD, and 3b) Closer as a family.

6.3.1 Sub-theme 3a: Closer to person with PD. Approximately half of the participants reported the PD caregiving experience had improved their relationship with the person with PD. These participants reported that the presence of PD had brought them close to their person with PD. For example, Dena reported:

I think in fact our relationship has strengthened since he has had Parkinson's, because I mean, you say it was strong beforehand but we had our problems, we had issues, you know, we had our arguments ((laughs)). But he has even said that himself, it has brought us closer together.

For these participants, their experience was that PD had increased the closeness or intimacy that they felt for their partner or family member with PD. For example, James concluded the PD caregiving experience had brought him closer to his wife, because of the intimacy and proximity involved in performing caregiving responsibilities and tasks associated with his wife's increasing dependence. James indicated that the challenges imposed by the disease had united them:

In many ways we are closer now than we ever have been (...) up to a point, it's been the result of the, of the, Parkinson's rather than despite it. Yes, she is a lot more dependent on me. And that has driven us closer together, and helps us to cope with everything else. There is a lot of intimacy involved in that. (P11: Husband)

Relationship growth was not limited to spousal relationships, but extended to adult children caring for their parents. Libby concurred that the PD caregiving experience had positively changed the relationship she shared with her father. Libby recalled during the interview that pre-PD her father was largely absent from their family home due to work commitments. Libby reported that her father was forced to relinquish his professional role

responsibilities because of the physical and cognitive limitations of the disease. Consequently he spent less time at work and more time at home with the family. Libby perceived that spending more time with her father contributed to the strengthened relationship and improved companionship:

We [Libby and her brother] didn't really know Dad that well ((laughs)) in a way, but over the years I've come to know him better and better, and, you know, I feel very close to him now, and I don't regret that. I really enjoy his company, and I enjoy teasing him and making him laugh and all that kind of thing.

Like Libby, many participants agreed that spending more quality time together resulted in becoming closer to the person with PD. Seemingly spending more time with the person with PD was a way of coping with the threatened loss of the person with PD and shared future. In many cases the PD diagnosis prompted the participant and the person with PD to spend more quality time together whilst the person with PD was still able to so. This appeared to be a conscious and mutual choice due to the re-evaluation and re-prioritisation process as mentioned in sub-theme 1a: Making the most of it.

Several participants recalled that they had engaged in more activities together since the PD diagnosis. Examples of activities included attending exercise classes, trekking, sailing and going on holiday together. Paul reported having commenced Tai Chi with his wife. This was seemingly motivated by efforts to better manage the disease and maintain quality of life. Paul believed he would not have considered attending Tai Chi exercise in the absence of his wife's PD diagnosis:

So in terms of doing things together, yeah, in one sense with the Tai Chi, and you know, I don't think I would have, I wouldn't have bothered ... it wasn't my thing to tell you the truth, or either of us. And going to a regular Pilates class, the same thing. I would not have done that either. I have never particularly been in to physical fitness.

Nonetheless, for others spending more time together was a natural development due to their stage of life (e.g., retirement), which may have naturally had a positive influence on their relationship. A number of participants believed their relationship with the person with PD was closer and stronger as a result of uniting together to deal with the challenges imposed by PD. These participants concurred that facing the challenges of PD together, working as a team, talking through things together, and learning together had strengthened their relationship.

Robert attributed increased closeness to performing tasks together, such as domestic chores, as in the past his wife had performed all these chores. Robert said:

I think with helping doing the cooking and helping doing the practical work instead of sitting on the side giving the orders, ((laughs)) it brings you closer together. Things I've never had to worry about right? And it is part and parcel we are both learning together now, so it makes a lot of difference.

A few participants also reported a greater appreciation for their person with PD since the presence of PD in their lives. These participants believed that the PD situation either provided an opportunity to see, or reminded them of the person with PD's personal strengths or positive personal attributes such as courage, will, and perseverance. For example, Dena described her newfound respect and admiration for her husband, because of the way he handled the disease:

But when he was diagnosed I recognised his strengths and appreciated him more, and I think I had to work at appreciating what he is going through with Parkinson's and why he can't to things. Certainly though, I have a lot of admiration for his determination. I mean, since he has been diagnosed he trekked through Patagonia for 11 days straight, with backpacks on for 7 days straight and up mountains, and he did that, taking medication every 3 hours, he is just amazing ... I have always respected

him very highly in other ways, like his capabilities of being a great engineer, a great father, but all of a sudden there was this other dimension.

Similarly, Alex admired the way his wife coped with the impacts of PD. He reported, “but on the other hand, it’s very uplifting to see how she handles it, hugely admirable.”

6.3.2 Sub-theme 3b: Closer as a family. Relationship growth was not limited to the relationship between the loved one providing care and the person with PD, but extended to other relationships with family members. Some participants considered that they already shared strong family bonds, but PD had brought them closer together because of the united efforts in caring for the person with PD. From these participants’ accounts, it seemed that family members contributing to caregiving could grow closer in the process. For example, Katrina reported:

Well, it’s affected our whole family. And we are lucky because we have four adult daughters, and we are a really close family. We are lucky because we were a close family to start off with, but the diagnosis just brought us closer, and closer together. They are very supportive.

Another participant, Tina (a 50-year-old single mother who cares for her elderly parents and whose father has PD), stated that in the past her mother was the primary carer for Tina’s father (person with PD). But since her mother experienced her own health problems, she was unable to independently care for her husband. Consequently, Tina assisted her mother in providing care for her father until her mother’s health declined. As a result, Tina began to provide care for both her parents until her father went into a nursing home, just prior to the current research interview. Tina recalled that prior to the shared caregiving arrangement, she and her mother frequently argued, but through shared caregiving combined with her mother’s ailing health, their relationship difficulties had resolved, and as a result, Tina reported feeling closer to her mother:

I've noticed how soft my mother really is. And, yes, my mother and my relationship, don't get me wrong I love my mother with all my life and I will love her until the day I die. My mother and I have always been the type to be at loggerheads. Because she wanted to win, I wanted to win, you know, that typical she says black and I say white and I win. But, more so now that Dad's got worse and he's in the nursing home, because I am talking to mum more often (...) I need to do what I can to make it comfortable for Mum, she is on her own now, ring her up once a day, she won't do it. And I feel as if my mother and I have gotten closer.

6.4 Master theme 4: Contextual Experience

The fourth theme pertained to various personal and contextual factors described by the participants as impacting their PD caregiving experience. Participants spoke in reference to: meaning made about the disease at the time of diagnosis, their developmental life stage and relationship stage, the person with PD experience, the stage of the disease (as mentioned above), the quality of the pre-PD relationship, past and current adverse experiences, and support groups.

6.4.1 Sub-theme 4a: Meaning made about PD at time of diagnosis. All participants spoke about their experiences at the time of diagnosis. Many participants recalled at the time of diagnosis that they had limited-to-no understanding or knowledge about the disease. The meaning-made about the disease at the time of diagnosis relied heavily upon the information provided by the diagnosing health professional, which in turn shaped their experience about the disease. Ten participants were informed (to the effect of) that PD was not a death sentence or a life threatening disease, rather a life limiting disease.

For example, Shelly recalled, "well his [the neurologist's] words to Dad [person with PD] were, 'you are probably going to get hit by a truck before the Parkinson's affects you'" (P9: Daughter). Consequently, some participants reported that they were relieved and

grateful that their loved one with PD was diagnosed with PD rather than a life-threatening disease, such as cancer or heart disease. Rosemary recalled their experience when telling their daughters about her husband's diagnosis: "They were upset but fairly quickly they got over that, because as he said, 'I could be telling you I've got cancer or a week to live because I've got a dicky ticker,' [laughs] which clearly wasn't the case."

Several participants were informed not to expect the worse because PD is a unique disease with a broad spectrum of symptoms, and not to worry or make any changes because their person with PD's disease trajectory may not be as bad or progress as quickly as they may imagine it would. Many participants were told to expect a slow disease progression, and that the disease could be managed by medication. For example, Beatrice was told to expect a slow disease progress as well as minimal negative changes. Unfortunately, as previously mentioned, this was not the case for her husband who experienced a rapid decline in cognitive functioning and was diagnosed with accompanying Lewy Bodies dementia. Nevertheless, Beatrice recalled a message conveyed at the time of diagnosis:

Well, in the beginning you like to think that nothing is going to change. You know what I mean? You know they say yes he's got Parkinson's. And they say it could be really slow and he may not change. It must just continue along that level. So in the beginning you may think that everything is fine.

Many participants recalled that they were largely unaware of possible negative impacts the disease would have on their lives at the time of diagnosis. Many made a mutual choice to carry on as normal and did not make any positive changes to their lives. Mary reported, at the time of the diagnosis, both she and her husband (person with PD) were unconcerned about it, and largely ignored it. Mary attributed it to him not knowing much about PD. Seemingly she knew more about it but did not want to stress her husband unnecessarily. She commented:

Well, when he was diagnosed, I just thought oh well, it's just something we've got to live with and it's not a life sentence, and he seemed to be unconcerned about, in fact he really ignored the whole thing for about two years. ... But he was okay about it, I don't think he really understood or knew much about Parkinson's so I didn't bother enlightening him because [laughs] I didn't want him to stress about it."

Martyn reported that he wished he had been more aware of the implications of the disease from the onset, and believe it would have influenced his life choices, and the way he interacted with this father (person with PD):

And when I look back there are things that I would have done differently, and I don't know about Deb, [sister – co-carer] or Dad, about whether they wish they could have done things differently. But I think just having that experience and going what do we do now, in comparison to what we did before, and if you have your time again would you do something differently? I think knowing what I do now, back then, I think it would have been completely different but I guess, I think that's the way of life isn't it.

6.4.2 Sub-theme 4b: Person with PD's experience. Nine participants stated that their person with PD's experience of the disease largely influenced their own experience. Dena responded, "you asked me what my experience was. I think my experience has been based on Adam's reaction to it, I think. You know, he is the kind of person doesn't give in" (P3: Wife). As Dena indicated, her husband's determined nature positively influenced her experience. Like Dena, other participants described how the person with PD's strengths and attributes (e.g., levels of acceptance, a positive attitude, an open mind, taking PD in his or her stride) also positively influenced their experience. It appeared that the persons with PD had a tendency to conduct themselves in ways that reflected their pre-morbid personalities or ways of coping. For example, Shelley stated, "nothing has ever worried him his whole life, so I

guess he is very lucky in that respect. He's been in very lucky he has that disposition where nothing has ever worried him."

Many participants described their persons with PD as highly motivated to maintain a sense of normalcy; a desire to remain as normal as possible, for as long as possible. Some described the person with PD's accountability to their families (including the participant). They described an aggressiveness for not letting the physical restrictions and limitations of the disease beat them. These participants described their persons with PD as being committed to remaining active and involved in order to maintain a normal life for as long as possible.

However, some participants said that their person with PD had taken, "living normally" to an extreme degree, which many participants conceptualised as denial. This manifested in a refusal to admit anything was wrong, to accept the disease or take medication. Darren reported, "they don't accept that they have a disease themselves. And very often don't want to know about the disease until later." Participants also reported that their person with PD largely ignored the symptoms and was also reluctant to attend the doctor despite the loved one's concerns and constant reminders. A few participants reported that it took a long time for their person with PD to accept the disease and commence taking the medication. James reported, "it took quite a while for her to accept it, and start to take any sort of medication". In addition, some participants reported that their person with PD refused to tell friends and family about the PD diagnosis. Katrina mentioned on numerous occasions during the interview that her husband did not want her to discuss that he had PD. She stated that this was challenging for her, as she seemingly had no one to express her feelings or concerns with. Katina stated:

As I said, he didn't want other people to know outside our family. In time we told our immediate family. We told my father. As I said, I was my Dad's carer too. Anyway

that's another story. He didn't want other people to know. He didn't want to be treated differently. He didn't want anyone looking at him differently. So a number of my close friends, you know, I wasn't able to talk to about it. But slowly, slowly he is dealing with it, and becoming able to accept it. But still not everyone knows. But if they ask, he will tell them. If they ask him, "are you alright?" if the medication starts to wear off, or if he has had a stressful day, he will tell them.

6.4.3 Sub-theme 4c: Quality of pre-existing relationship. Many participants believed the quality of their relationships with their persons with PD were good. These participants referred to the quality of their relationship with the person with PD as being an important and positive aspect of their caregiving experiences. Some participants already professed to having a good relationship with the person with PD prior to the onset of PD, but reported that the PD experience had enriched their relationship. David said, "we've always been close, but now it is much, much better." Several participants believed that having a strong relationship was beneficial or even vital for coping and adjusting to PD. For example, Hannah reported, "we have always had a very good relationship and that is certainly vital when someone has PD."

6.4.4 Sub-theme 4d: Support groups. Many participants reported attending PD caregiving support groups. Of these participants, some described support groups as essential in helping them deal with having a loved one with PD. Participants described numerous motivations for attending a support group, primarily for knowledge acquisition about the nature, treatment and management of PD with the aim of providing competent care. These participants reported that support groups allowed them to keep up-to-date with treatment and research advancements, as well as learning incidental things that these participants concurred could only be garnered from people who had directly experienced PD and the PD caregiving situation (which a health professional may not impart).

Other participants, like Susan, initially attended a support group to seek validation from others in a similar situation. In Susan's account, she described her willingness to learn more about the disease trajectory. Conversely, her husband was reluctant to attend because he feared it would be confronting, and preferred to take things day-by-day:

I mean, there was a time when I wanted to go to a support group, but Terrace didn't want to go because he had heard of an experience like you [referring to Noel, another attendee at the focus group, when he found it confronting seeing people who were severely impacted by PD at the support groups], when someone had gone and learned how bad it was for him. He was different; he was just going to take it day-by-day. But for me, I said I was going to join up to this Parkinson's [support] group that had started locally, and I wanted to join it, because I needed to know what other people were experiencing and feeling and I needed to know if I was going through the same thing. If my feelings are real, or am I confusing Parkinson's with old age, or have we just been together too much, I wasn't sure so I think I needed to know, so I went along, and he has gone along, and he actually loves it. It's a good group and we don't have anyone in the group who is too frightening or scary down the track symptoms.

For Susan's husband, and for other persons with PD, once they had finally attended a support group, they reported the benefit of attending. Although one participant, Andie, stated that she was advised by her treating specialist not to research PD, or join a support group (seemingly a protective act) because they would not see anyone getting better:

The neurologist that we go to, he is a really nice man. Very um, "to the point," but he said to us, right at the very beginning when Rob was first diagnosed, when Rob was much, well obviously he was more well than he is now. Um, and he said to us, "do not look up anything." He said, "do not join any support group." He said, "I will tell you as we go through this, what you need to know." And um, yeah. And I did not

listen to him, and I did jump on the Internet, and after, you know, a few days of getting on and looking at different things I thought no, I'm not doing this anymore [laughs]. And he said to us not to join any support groups, because he said you are not going to meet anybody who gets better.

In addition to gaining knowledge, validation and support from the PD support groups, many participant also reported that the support groups provided an opportunity to contribute positively to group attendees by sharing their own experiences, imparting knowledge, providing emotional support, and fostering hope and optimism. Through contributing positively to others in the group, it seemingly restored the participants' sense of usefulness and worthiness, and gave their life meaning. During the focus group, Terry noted and Susan agreed:

"Sometimes with the support group it's not what they can do for you, it's what you can do for them." (Terry)

"Well that's it." [crosstalk] (Susan)

"Because you have gone there and you can pass your information on." (Terry)

"That's right." [crosstalk] (Susan)

"Some silly little bit of information, which people may have heard several times, and others may go, oh really, it's that simple is it to do?" (Terry)

6.4.5 Sub-theme 4e: Past and/or current adverse experiences. Sixteen participants, without direct prompting, volunteered that they had been exposed to past adverse life events (e.g., heart attack; longstanding chronic health condition accompanied with previous near fatal health scares; death of a loved one; previous caregiving experiences, where some had eventuated in the relative's death). Some participants were concurrently dealing with adverse life stressors, such as an ongoing battle with breast cancer or family stress. All of these individuals described a growth experience associated with past adversity,

such as becoming stronger, a positive change in attitude and approach to life and relationships (e.g., family), or a greater sense of gratitude and appreciation and a greater sense of satisfaction from life.

For example, Katrina reported that her ongoing personal battle with breast cancer had positively changed her perspective on life. She reported focusing more on the positives rather than the negatives, making the most of each day, and living in the present moment:

In [year] Graham was diagnosed. In [year, one year after PD diagnosis] I was diagnosed with breast cancer. So, yes, it'll be five years in [name of month] I will be clear. And with that too, you just realise how lucky you are and live each day like it's your last, well not your last, but everything is beautiful. You look at the beauty in life, and not the negativity I suppose, and you've just got to get out and really see things. And appreciate what you have in life, like your family and all those little things.

Similarly, during Shelley's interview (a 49-year-old single, fulltime finance officer, who provides care for her elderly parents. Her father was formally diagnosed 5 years prior to current interview) she reported that she had lived with a longstanding heart condition since birth. Shelley underwent major heart surgery, which resulted in major complications. Shelley believed that her health condition and near death experience had provided an impetus to make the most of each day, and be grateful for the gift of life. Shelley responded to the following interview question:

"What do you think it is about you and about your character – your own personal attributes that have stood you in good stead, and that enables you to keep persevering and getting by?." (Interviewer)

"I don't know. I guess, I've been dealt a few health scares in my life; I was rushed in for emergency heart surgery when I turned 40. So that I've had a something wrong

with my heart since I was born, and had that, and I just, you know, went in and had it done and, come out and came through it. Yeah so-” (Shelley)

“Did that change your philosophy a little bit Shelley?” (Interviewer)

“It probably did. Um, yeah I had, I lived overseas when I was younger, just out of school and uni or whatever it was, and I didn’t see them for a while, and there were, I saw a lot of things and dealt with a lot of things, became a lot stronger I guess. Even though as a child we were, had a pretty open family I was probably shyest the most out of everybody, but when I started travelling and experiences I realized well I’m on my own and I’ve got to deal with this. And I guess the way I deal with it, and I guess that was what pulled me through and I guess that is what gets me through now. It made me a lot stronger, the travelling, it certainly made me a lot stronger when I had to do it and I only had myself to rely on, and I think that has made it a lot easier and yeah. I don’t know. I don’t think I am any different to anyone else.”

Shelley went on to say:

We get dealt a lot of things in life and my heart surgery then two years to the day after my heart surgery I found out I had deep vein thrombosis and I had two pulmonary embolisms. They told me that if it had been another three hours I would have been dead. Yeah. So, I guess that both of those experiences were a bit of wake-up call, and I thought well if I can get through them then I am here for a reason and I’m going to make the most of every day. And everything else, that my travel and all that taught me, and up until then, yeah I just try to make the most of each day and get on with it and deal with it and be happy that I’ve got a day to deal it.

It was evident in Shelley’s account that she was forging meaning for why she had endured the adversities of her own personal ill health and others in her life. Her own longstanding health condition and her near death experience, combined with the ill health of

others (i.e., her father being diagnosed with PD) made her aware of the fragility of her own existence. These factors provided impetus to travel, even though at the time, she described herself as a shy and timid individual. These experiences taught her that she was more capable and stronger than she previously thought, and this gave her more self-belief and a sense of self-sufficiency and self-reliance, which seemingly served her in the current PD caregiving situation.

Similarly, Jean reported that she had been providing longstanding care for her brother who has Down Syndrome since her mother died. Jean perceived that this experience had provided her with strength and a will to research and understand the disease, which seemingly assisted in her current PD caregiving situation with her husband:

I think fighting for my brother's rights all my life that, you know, there was a lot of stuff that was really difficult over the years. And we don't have any other siblings and I think just having to deal with that gives you the strength and also gives you the will to find out and to know how to do it and it really helped dramatically I think.

6.4.6 Sub-theme 4f: Developmental life and relationship stage. Some participants in spousal relationships with the person with PD indicated the positive changes or improved relationship with that person could be partly attributed to the length of time they had been married, and the natural development of the relationship that came from being married, rather than the presence of PD in their lives or the PD caregiving situation. Terry responded at the focus group when questioned about the impacts of PD on his relationship with his wife:

We work better as a team. We seem to know how one-another thinks, and we seem to work together. As Penny says, she couldn't, I don't think she could function without me. So we seem to function together. Whether it's because we have been married for so long? We seem to know what one-another is thinking, and what the other is doing,

and it seems to come naturally. Whether it's, you know she has had the Parkinson's for 18 odd years. And you just grow together with what you do.

Some participants made assumptions that their increasing age may have impacted their spousal relationships. For example, Darren reported the frequency and intensity of the arguments changed over the years becoming less often, which he attributed to increasing age:

"I would say they [arguments] are different. I think there aren't as many certainly.

Yes, but we're older but, we used to have blow-ups." (Darren)

"You've mellowed a bit ((laughs))." (Interviewer)

"Yes I've mellowed. But it's true. You might have fights about other things. Like if someone forgets to take the medication, you may have a fight over that. It's important that you think of these things. ... Whereas in the past it might not have been an issue. So, if you do have some differences in opinion, they are probably slightly different than they would have been in the past you know?" (Darren)

"Yeah, yeah. The types of issues and arguments have changed?" (Interviewer)

"Well, in any relationship there are always ups and downs, areas of tension, and areas of discontent, and that sort of thing. Probably a little different and certainly not as frequent as you take things on board more, and so see bringing things up as quite so necessary. And you deal with differences of opinion in different ways ((unclear)). like if she does something that I consider something that is unsafe then I have a go, whereas I wouldn't have considered that a few years ago." (Darren)

6.5 Master theme 5: Lacking in Positive Changes and Growth-ful Development

While many participants reported experiencing positive psychological changes and growth-ful development as a result of PD caregiving, other participants did not report any positive changes in their lives. Rather, these participants stated that there had only been negative impacts and losses associated with having a loved one with PD. There were also

some participants who could not identify any changes as a result of PD, neither positive nor negative changes.

6.5.1 Sub-theme 5a: No positive changes, only negative. A few participants were unable to describe any positive experiences associated with having a loved one with PD, or PD caregiving. These participants explicitly stated that there was nothing positive to come from their loved one being diagnosed with PD. In fact one participant, Zara, appeared offended when asked about any positive impacts of PD. She stated it was an odd question, and could only identify the negative aspects of PD. For these participants, their accounts focused predominantly on the personal and/or relational strains and losses associated with the PD caregiving experience.

Whilst some participants reported relationship growth as a result of the PD caregiving situation, there were a few participants who stated the quality of their relationships with their persons with PD, as well as family members and friends, had only declined. The accounts of these participants focused on relational losses associated with PD, such as the loss of physical and emotional support from their persons with PD, decline in the quality of communications and interactions with those persons, as well as loss of relationships with friends and family. For example, Beatrice (a 58-year-old wife whose husband was formally diagnosed with PD 6 years prior to the date of the research interview) cared for her husband who at the time of the interview had recently been undergoing assessment for Lewy Bodies Dementia, a type of dementia that is prevalent in PD, as a result of his rapid decline in cognitive functioning. Apparently her husband's prognosis was grim, and she was informed that he might die within 12 months. Beatrice reported that nothing positive had come from her husband's disease, and did not believe PD had brought them closer together:

Do you know I don't think there is [any positive effects of PD], no. I know some people say when they get a chronic illness it brings them closer but I just feel like this

whole thing, that I have been left in the dark so much and I feel this whole thing, and as far as him having Parkinson's no! We have always been super close. We have worked together 7 days a week 24 hours a day. For the last 14 years. So no, I don't think it has been positive at all (...) It's [relationship with husband] changed so much, I have to take so much more responsibility and I mean, I will never stop loving him and I know how he is now, it's not him, it's the Parkinson's.

Zara reported that the relationship with her husband had deteriorated since he had undergone DBS surgery. Prior to DBS she described a happy and contented relationship. Zara reported that the quality of their relationship had not changed since her husband was diagnosed, until after the surgery. Since the surgery, Zara described her husband as being emotionally unsupportive and lacking in warmth and affection, which in turn placed a strain on their relationship and resulted in a trial separation. When questioned about the most difficult aspect of having a loved one diagnosed with PD, Zara responded:

I think the lack of emotional response from my husband. I was prepared to do anything [for him], and I still am. But when there are no emotions there, that's the most difficult thing of the lot. The lack of sympathy, the lack of warmth. I know he said to Professor X [treating neurologist], "I know I love my wife, but I don't feel it."

In addition, Alesha did not report any relationship growth, only strains. It appeared that their relationship has always been conflict-laden, even prior to the PD caregiving experience.

Alesha reported:

Well, the relationship has certainly changed, I feel like I'm more of a carer now than a wife. I don't see him as a husband anymore, that role has changed. Probably because of the fact that I said to you it seems to become that they're just more concerned about themselves, I can't even have a bad day and do a ranting and raving because if I do that he always seems to turn it around to him, that I'm criticising him,

and I said, “Gee, I can’t even have a bad mood day any more now on my own, without you making out that it’s all about you!” because my bad mood day would affect him so he’s more concerned about that- that it affects him, than me being in a bad mood ((laughing)). So definitely that’s all changed, I don’t feel that there’s any concern about you at all, I could drop dead and I often think, would he have enough energy to phone the ambulance, that’s how bad I feel it is sometimes.

Notably, as illustrated in previous themes, Alesha did report many examples of positive changes in perspectives on living and personal growth (i.e., becoming more patient), whereas all the other participants in this sub-theme did not report any positive as result of the presence of PD in their lives.

6.5.2 Sub-theme 5b: “PD doesn’t interfered with our lives or relationship.”

When questioned about the impact of PD on their lives, some of participants reported that PD had not impacted upon their lives. They stated that there had been no positive or negative changes as a result of their loved one being diagnosed with PD. These participants thought this was because of the slow and gradual disease progression. This meant that any change was gradual and often unnoticeable and perceived the changes as being minimal and not significant. These participants reported that during the early stages the medication masked the symptoms and allowed the person with PD to function relatively normally, and they continued to perform role responsibilities and household tasks without requiring much assistance. The slow progression of the disease, as well as the medication masking the symptoms, allowed for a false sense of normalcy, which appeared to contribute to a sense of no change during the early stages in contrast to other participants. Whereas those participants whose persons with PD were in the more advanced stages of the disease, and had been providing substantially more assistance, reported personal growth arising from a sense of

accomplishment, competence, acquiring or deriving skills, or mastering tasks associated with roles and responsibilities required for caregiving.

Some female participants believed that they had not experienced any personal growth or acquired any new skills during the caregiving experience. In these cases, they reported that their husband's physical and cognitive functioning was substantially impaired by the disease, yet these participants did not feel they were doing anything differently because they had always assumed all or the majority of the household tasks. Therefore, they did not believe the PD caregiving situation had provided an opportunity for personal growth.

For example, when Alexandra (an 82-year-old housewife, whose 87-year-old husband was diagnosed with PD 4 years prior to the research interview) was questioned about whether she had experienced any personal growth or developed any new skills since her husband was diagnosed. She responded, "no really, no. Well I have always done everything. I do a little more I suppose. I get a bit tired I suppose, now and again, but that is to be expected. You've got to keep going." Similarly, Catherine (a 70-year-old retired nurse, whose 75-year-old husband was diagnosed approximately 10 years prior to the current research interview) responded, "not really, because I've always mowed my lawns, I've always done everything ((laughs))."

6.6 Summary

Qualitative analysis revealed that the vast majority of participants could identify something positive about having a loved one diagnosed with PD and/or the PD caregiving situation. However, a small number of participants could not identify any positive or growthful experiences; rather they only reported negative consequences. Some participants stated that PD had not interfered with their lives, and therefore could not acknowledge any positive or negative impacts of PD on their lives, neither personally nor relationally.

Chapter 7: Discussion

The Discussion chapter presents the interpretations and explanations for the findings (master themes and sub-themes), utilising theoretical models of growth in the context of existing literature. Five master themes and 20 sub-themes were identified in the analysis. The five master themes are: (1) positive changes on perspectives on living, (2) personal growth, (3) relationship growth, (4) contextual experience associated with positive changes and growth-ful development, and (5) lacking in positive changes and growth-ful development.

Each of these master themes and sub-themes will be explained briefly in relation to the study's research aims and assumptions. Each master theme and sub-theme will be extensively explained in two sections. First within the broader context of the existing caregiving literature, which highlights both novel and unexpected findings and serves to demonstrate the present study's contributions by extending existing research. Secondly, each master theme and sub-theme will be interpreted and explained using growth theories introduced previously (namely AAD; Papadopoulos, 2007; PTG; Calhoun, Cann, & Tedeschi 2010; and the revised meaning-making model Park, 2010), as well as other relevant psychological theories. In accordance with the theoretical commitment of IPA, psychological knowledge and theory was used to explain and interpret participants' accounts only when raw data invited it.

The present study has highlighted the relevance of providing a more encompassing depiction of the PD caregiving experience due to the pre-existing negative attentional bias of conventional PD caregiving research. The first aim of this study was to elucidate the lived experience of the loved ones providing care for persons with PD. The second was to explore whether the loved ones report self-perceived positive experiences and growth-ful development associated with PD caregiving. This study was informed by the assumption that

loved ones providing care would report positive psychological experiences and growth-ful development. In support of this assumption, caregivers' responses revealed that there can be positive experiences and growth-ful development associated with PD caregiving. Findings established that positive experiences and growth-ful development associated with PD caregiving were present for many participants, but not present for a small number of participants as represented in the master themes and sub-themes. Overall, the data indicated that many loved ones providing care underwent a series of psychological, emotional, cognitive, interpersonal and occupational changes once a loved one was diagnosed with PD, and when undertaking the caregiver role. These changes were not limited to negative effects, such as caregiver burden (e.g., Aarsland et al., 2007; Caap-Ahlgren & Dehlin, 2002; Harbishettar et al., 2010), depression (e.g., Carter, Stewart, Lyons, & Archbold, 2008; Goldsworthy & Knowles, 2008; Martinez-Martin et al., 2008), health problems (e.g., K. S. Kim et al., 2007; Lau & Au, 2011; McKinlay et al., 2008), personal and relationship loss (e.g., Cifu et al., 2006; McRae et al., 2009), and diminished quality of life (e.g., Kelly et al., 2012; Morley et al., 2012; O'Connor & McCabe, 2011); but there were positive, life-affirming changes. Nonetheless, a lesser portion of participants believed that they did not experience any change either positive or negative, and a small number only reported negative changes.

The third aim was to shed more light on the positive psychological and cognitive (meaning-making) changes reported by the loved ones, by explaining how they made positive sense and ascribe positive meaning to both the experience of having a loved one diagnosed with PD, and the PD caregiving experience. The sub-themes within each master theme serve to illustrate the nature of this adaptive process. That is, what type of life re-evaluations or self- perceived changes in personal attributes and skills took place as a form of positive psychological change and growth-ful development under the strain of PD caregiving.

This chapter is structured to address the fourth and final aim, to examine ways in which findings support and contribute to growth theories in the context of PD caregiving.

7.1 Master Themes and Sub-themes in the Context of Caregiving Literature

7.1.1 Master theme 1: Positive changes in perspectives on living. The first of the five master themes pertained to positive changes in perspectives on living since the presence of PD in the participants' lives. These changes encompassed trying to make the most of life (sub-theme 1a: *"Making the most of it," through re-evaluation and reprioritisation*), engaging in meaningful pursuits in accordance with personal values (sub-theme 1b: *"Finding meaning in caregiving," through benefit-finding and meaning-making*), becoming more appreciative of personal circumstances and relationships (sub-theme 1c: *"We're the lucky ones," greater sense of gratitude through social comparison*), developing a strong desire to contribute positively to others (sub-theme 1d: *"Touched by Parkinson's," the desire to positively contribute to those affected by PD*), and becoming more accepting of life's ambiguities and the things outside of personal control (sub-theme 1e: *"Just got to accept it," greater acceptance of the ambiguous nature of PD and life in general*).

7.1.1.1 Sub-theme 1a: "Making the most of it," through re-evaluation and reprioritisation. This sub-theme contains the loved ones' responses reflecting an existentialist life re-appraisal and resultant behavioural manifestation (i.e., spending more time with person with PD), which is also found amongst dementia caregiving studies (e.g., Peacock et al., 2010; Sanders, 2005). Specifically, for many loved ones the knowledge of the PD diagnosis and the impending limitations and restrictions imposed by PD, brought about a heightened sense of vulnerability, fragility and finiteness of human existence. This served as a reminder of the preciousness of life and prompted loved ones "to make the most of it" by devoting more quality time to their person with PD. Levine et al. (1984) explain this process as chronically ill patients and their loved ones being deprived of the atmosphere which makes

normal repression of the fear of death possible. At the same time, the threat of imminent loss and diminished quality of life highlights one's existential desire to live a meaningful life.

7.1.1.2 Sub-theme 1b: “Finding meaning in caregiving,” through benefit-finding and meaning-making. Positive psychological change as an adaptive function due to exposure to adversity was also elucidated by this sub-theme. This is consistent with existing dementia caregiving literature (Farran et al., 1999; Netto et al., 2009; Nolan, Grant, & Keady, 1996) that shows caregiving provided loved ones with an opportunity to meet existential needs of finding meaning or purpose in life. Ross, Holliman and Dixon (2003) suggest that caregivers' beliefs that their purpose is to care for their loved one helped them to concentrate on the positive, rather than negative, aspects of caregiving. Also, Blanchard et al. (2009) found that adult-children providing supplementary care to parents with PD expressed a greater ability to see the positive aspects of their personal circumstances due to their caring role. Blanchard et al. suggested that positivism was essential for adjustment and coping in the PD caregiving situation, and this was a unique finding in the PD literature. The findings by Blanchard et al. could not be previously generalised to the primary caregiver because of the supplementary nature of the caregiving role of adult-children. Providing supplementary care is arguably less frequent and intense than that of primary, spousal carers. However, the present study bridged this gap in the literature by demonstrating that primary, spousal caregivers are also able to experience positive psychological outcomes that assist adjustment difficulties.

7.1.1.3 Sub-theme 1c: “We're the lucky ones,” greater sense of gratitude through social comparison. In recognising the preciousness and finiteness of life, loved ones expressed a new found appreciation and gratitude for life, encapsulated within this sub-theme that is consistent with other PD studies (Blanchard et al., 2009; Chiong-Rivero et al., 2011; Hodgson et al., 2004). This illustrates another way in which positive psychological changes

(namely a sense of relief and gratitude) were derived from caregiving adversities (namely the stress associated with the PD diagnosis) through the recognition that other diagnoses such as terminal cancer or leukaemia are worse than PD. Similarly, McLaughlin et al. (2011) found that a PD sufferer's loved ones described a heightened sense of worry and uncertainty in the lead up to the PD diagnosis. When the PD diagnosis was finally confirmed they were initially shocked, but then felt relieved and thankful that the diagnosis was not as bad as they had initially expected and feared.

Hodgson et al. (2004) also noted the positive psychological experience of gratitude, which they termed *thankfulness*. Hodgson and colleagues identified that this was a unique finding in the PD caregiving literature and called for further exploration. The present study filled the gap in the PD literature by revealing that social comparisons can influence the experience of gratitude amongst persons with PD and their loved ones providing care in the following way – if caregivers employ “downward” social comparison (Taylor, 1983) that is, appraised “others are worse off than us,” this resulted in reporting a sense of gratitude.

7.1.1.4 Sub-theme 1d: “Touched by Parkinson’s,” the desire to positively contribute to those affected by PD. This sub-theme contains carers’ responses reflecting that they had been touched by PD and experienced a new found desire to contribute positively to others affected by PD, which again resulted in behavioural manifestation (i.e., becoming involved in the PD community and raising money for PD charities). These behavioural manifestations further provided loved ones with a restored sense of usefulness and purpose in life in response to having a loved one affected or die from an illness, which was also found in numerous caregiving studies (e.g., Carlisle, 2000; Netto et al., 2009; Sanders, 2005).

7.1.1.5 Sub-theme 1e: “Just got to accept it,” greater acceptance of the ambiguous nature of PD and life in general. The loved ones’ responses comprising this sub-theme revealed that over time, loved ones gradually came to accept not only the ambiguous nature

of PD, but also increased their tolerance towards existentialist ambiguity. That is, an acceptance that ambiguity is a feature of life itself for all human beings. “Acceptance” in this context refers to an ability to tolerate multiple losses imposed by PD including, but not limited to, loss of a shared future; relationship roles; ability of the persons with PD to provide physical and emotional support to the loved ones; and personal identity, employment and quality of life (of both the loved ones providing care and person with PD). This sense of acceptance was partly due to the cognitive process of recognising that there are many things that could not be controlled (e.g., the disease trajectory), but the way they chose to deal with that PD situation was indeed within their control (e.g., through focusing on positives).

Responses captured within this sub-theme illustrate how the positive psychological gain of acceptance is both a product of the caregiving process and a maintaining factor in regards to sustaining the caregiving role. This was also found in the Singaporean study by Tan et al. (2012), which showed acceptance was essential for the caregivers’ ability to cope and adjust to the demands of their caring role. In the present study, acceptance was more apparent amongst bereaved caregivers, longer term caregivers, and those who had been providing care for loved ones in the more advanced stages of PD. It appeared that the uncertain and unpredictable nature of PD provided impetus to change their perspectives or orientation towards uncertainty, leading to a greater acceptance that certain things in life cannot be controlled. As a result of this accepting attitude, some loved ones providing care stated that they had become more laid-back, easy going and tolerant. These changes in personal attributes and interpersonal skills are explored further within the following master theme.

7.1.2. Master theme 2: Personal growth. This theme clearly demonstrates how positive psychological outcomes and growth-ful developments have been produced by the caregiving experience in the form of interpersonal skills and self-attributes.

7.1.2.1 Sub-theme 2a: Improved interpersonal skills. Interpersonal skills identified by the loved ones providing care included increased patience, empathy, compassion, listening skills, assertiveness, sensitivity and respect towards the needs of others, many of which were also found as a product of dementia caregiving (Netto et al., 2009; Sanders, 2005). Self attributes included becoming more flexible to common caregiving problems, gaining knowledge and a sense of empowerment regarding PD management, and becoming not only emotionally resilient but emotionally stronger.

Present study findings indicated that by becoming more compassionate and empathetic, the loved ones providing care were more sensitive to the needs of others (namely the person with PD), and as result considered themselves to be less selfish. Becoming more compassionate as well as sub-theme 1d: *“Touched by Parkinson’s,” the desire to positively contribute to those affected by PD*, is consistent with a recent study that found that newfound compassion a highly salient PTG domain after prostate cancer. Newfound compassion for others with cancer was also evidenced in a variety of cognitions and behaviours including becoming an advocate for cancer awareness, volunteer work, greater empathy and donating time/money to research (Morris, Shakespeare-Finch, & Scott, 2012).

In the present study, it is suggested that these areas of personal growth are a result of a common caregiving problem described by the majority of participants, as difficulty in finding a balance between providing care whilst maintaining maximum independence for the person with PD. This conflict was often accompanied by feelings of frustration, uncertainty, helplessness and loss of control. It appears that loved ones tried to regain a sense of control by employing problem-focused coping strategies, such as physically assisting their person with PD in activities for daily living and self-care. This can create tension between the caregiver and the person with PD if the caregiver’s efforts to assist do not accurately match the person with PD’s needs for autonomy and self-efficacy. Loved ones providing care had

to learn to be selfless (in regards to letting go of problem focused coping strategies which result maintain positive self-regard such as feeling useful) and more sensitive to the person with PD's personal boundaries and self-autonomy. Developing a greater sensitivity and awareness of the person with PD's existential needs or *ultimate concerns* (Yalom, 2008; Yalom & Lieberman, 1991) such as freedom, choice, responsibility, meaning, independence and autonomy, is a novel finding that is particularly unique to the literature and warrants further exploration.

7.1.2.2 Sub-theme 2b: More knowledgeable. Another example of personal growth identified by the loved ones as a product of their caregiving experience was becoming more knowledgeable since the PD diagnosis, and throughout the PD caregiving journey. This finding is congruent with PD caregiving studies by Blanchard et al. (2009) and Hodgson et al. (2004), and dementia caregiving studies by Netto et al. (2010) and Sanders (2005), who also found that at the time of crisis loved ones sought knowledge to empower themselves to help cope with these chronic conditions. Improved self-awareness and self-knowledge is also a unique finding in the PD caregiving literature warranting further investigation.

7.1.2.3 Sub-theme 2c: More adaptable. Another example within the second master theme of personal growth reported by carers was becoming more flexible to common caregiving problems (such as difficulty in providing care whilst maximising the person with PD's independence) due to the unpredictable and constantly changing nature of the disease. Previous PD caregiving studies (Chiong-Rivero et al., 2011; Dyck, 2009; Wressle et al., 2007) also found that the unpredictable and constantly changing nature of PD placed an emotional burden on the loved ones providing care for persons with PD. Improved adaptability was found in previous dementia caregiving studies (e.g., Peacock et al., 2010), although it is a unique finding in the PD caregiving literature, and warrants further exploration.

7.1.2.4 Sub-theme 2d: More capable and sub-theme 2e: Emotionally stronger.

Some loved ones reported feeling more capable as a result of performing tasks and roles that were previously performed by the person with PD. As a result, loved ones described feeling a greater sense of mastery, achievement, and emotional strength. Longer-term caregivers and caregivers of loved ones who had passed away reported more examples of ways in which they had personally grown due to the intensity of their involvement of care, as compared to participants whose person with PD was in the disease's earlier stages. Sub-theme 2d supports the assumption that the more adversity experienced the more opportunities for personal growth. This is consistent with previous findings from dementia caregiving studies that found self-perceived personal growth was positively correlated with the frequency and intensity of caregiving tasks performed by the caregiver (Leipold et al., 2008; Liew et al., 2010; Robertson, Braungart, Zarit, Stephens, & Femia, 2003). As intensity of tasks increased, measures of personal growth also increased (Leipold et al., 2008; Liew et al., 2010; Robertson et al., 2003). This finding suggests that the greater the caregiving demand, the greater the opportunity for frequent and close proximity with the care-recipient. This presents more opportunities to express altruism, which in turn results in an enhanced sense of self-competence, mastery, achievement and usefulness (Leipold et al., 2008). This explanation is supported by previous PD caregiving studies (Aarsland et al., 1999; Carter et al., 1998; D'Amelio et al., 2009) showing a positive correlation between caregiver burden and the advancing stages of the disease, in which measures of self-growth increased with increasing measures of burden.

7.1.3 Master theme 3: Relationship growth. This master theme included loved ones' reports of enhanced relationships with their persons with PD and with other family members, consistent with findings from dementia caregiving studies (e.g., Netto et al., 2009; Peacock et al., 2010; Sanders, 2005) as well as PD caregiving studies involving adult

children providing care for parents with PD and AD (Habermann et al., 2013), Singaporean PD caregivers (Tan et al., 2012), couples living with PD (Hodgson et al., 2004) and adult children providing supplementary care for a parent with PD (Blanchard et al., 2009).

The present findings revealed that participants who described positive changes in attitude (i.e., becoming more tolerant or appreciative of the person with PD and/or their family), personal strengths (e.g., coping with a sense of humour), as well as personal growth (e.g., increased patience, empathy and compassion) as a result of caregiving also reported harmonious relationships. It is hypothesised that the nature of the relationship between these various positive psychological experiences is interrelated, warranting further investigation (as explored in greater depth in Chapter Eight). That is, carers reported positive changes in perspective and personal growth, which contributed to relationship improvement, (e.g., being more patient brought them closer to their persons with PD). Furthermore, a better quality of social support provided by pre-existing positive family relationships was also reported to increase caregivers' perceptions of positive outcomes from the caregiving experience, as revealed by sub-theme 4c: *Quality of pre-existing relationship*.

Other researchers have also uncovered the positive impact of personal growth factors on relationships amongst various dual relationships in the caregiving literature (Habermann et al., 2013; Hodgson et al., 2004; Tan et al., 2002). Unlike the findings from Hodgsons et al. (2004) that suggest PD couple participants felt that PD had saved their relationship, none of the participants went as far as saying PD had saved their relationship. Rather, they stated that their relationship was already close, but they had become closer as a result of PD, both to the person with PD and their family.

7.1.4 Master theme 4: Contextual experience associated with positive changes and growth-ful development. The fourth master theme pertained to contextual factors that appeared to be associated with positive psychological changes and growth-ful development.

It was not the goal of this study to identify why some loved ones providing care report growth-ful developments and why others do not. Nevertheless, this theme went some way to gaining a better understanding of what factors may be more likely to elevate self-perceived positive psychological changes and growth-ful development. Contextual factors include those associated with meaning-made about PD at the time of diagnosis (cognitive factors); factors associated with the nature of PD (PD related factors); factors associated with the persons with PD (persons with PD factors); factors associated with the love one's relationship with the person with PD (social factors); and occurrence of past adverse/stressful life events, and the developmental life and relationship stage of the loved ones providing care (socio/developmental factors).

7.1.4.1 Sub-theme 4a: Meaning-made about PD at the time of diagnosis. The knowledge and understanding that loved ones had about PD at the time of diagnosis is relevant in determining self-perceived positive psychological changes and growth-ful development in the following way. It appeared that messages/information conveyed about PD by the diagnosing specialist influenced meaning-made about the PD diagnosis and in turn influenced positive outcomes and growth-ful development. It was observed in participant accounts that many loved ones were informed that PD was not a life-threatening disease, and that their life would remain normal because the PD sufferer's functioning would not diminish for approximately 10 years through proper medication. It appeared that the diagnosing specialists had a tendency to put a positive spin on the PD diagnosis, seemingly in an effort to allay worry and anxiety rather than fully informing them about the debilitating nature of the disease. This could account for why some loved ones made positive changes to their lives following the PD diagnosis as evidenced in sub-theme 1a: *"Making the most of life," through re-evaluation and re-prioritisation*, or why they did not make or experience any

positive changes as evidenced in the sub-theme 5b: *PD doesn't interfere with lives or relationship*.

7.1.4.2 Sub-theme 4b: Person with PD's experience. Pre-existing personality factors of the person with PD that influenced the loved ones' caregiving experience was encapsulated in this sub-theme. Similar to previous caregiving studies (Hansen, Slagsvold, & Ingebreetsen, 2013; Moore et al., 2011; Teixeira & Pereira, 2013), the present study found the experience of those indirectly affected by the disease or health condition was largely influenced by the experience of those directly affected (patient). Like Hodgson et al. (2004), participants in this study also expressed that the caregiving experience was made easier because their person with PD never complained about PD, and because they admired them for their strength and determination. The Hodgson et al. study may have been influenced by responder bias (the spouse feeling pressure to say positive things about their loved one with PD) as spouse and persons with PD were interviewed together. However, the replication of the Hodgson et al. finding within the context of the current study's separate interviewing processes has debunked this responder bias explanation.

Weiss (2004) conducted a correlational study focused on post-traumatic growth in breast cancer survivors and their husbands. Weiss found that the wives' reports of positive psychological changes and growth-ful development were a predictor of positive psychological changes and growth-ful development in their husbands. In other words, if the wife perceived she had grown as a result of the diagnosis, the husband was more likely to also report personal growth. It was concluded that the couples jointly faced the adversity associated with cancer, and their experiences were closely linked. This finding was consistent with other cancer caregiving longitudinal studies (Manne et al., 2004; Moore et al., 2011). Moore et al. (2011) suggest that the high level of agreement in self-perceived positive change and growth-ful development ratings between patient and spouse indicated that: (1)

there is increased likelihood of an individual reporting positive change in his or her spouse if they too rate themselves high on positive change, (2) individuals who experience positive change may be more likely to partner with individuals who are also more likely to experience positive change following a traumatic event, or (3) the patient or spouse may influence each others' level of positive change following a traumatic event.

7.1.4.3 Sub-theme 4c: *Quality of the pre-existing (pre-PD) relationship.* Responses contained within this sub-theme indicated that the quality of the pre-PD relationship appeared to be associated with self-perceived positive psychological changes and growth-ful development. Many participants reported that their relationship with the person with PD was already close, but became closer since the diagnosis. This sub-theme underscores the quality of the relationship, which is consistent with numerous studies across caregiving populations that found caregivers' positive pre-existing relationships predict growth-ful development associated with cancer caregiving (e.g., Manne et al., 2004; Moore et al., 2011; Weiss, 2004), dementia caregiving (Leipold et al., 2008; Liew et al., 2010; Pinquart & Sörensen, 2004), and providing care for an elderly relative (Hansen et al., 2013; Shirai, Koerner, & Kenyon, 2009; Toljamo, Perälä, & Laukkala, 2012).

7.1.4.4 Sub-theme 4d: *Past and/or current adverse experiences.* Responses comprising this sub-theme indicated that loved ones recalled how they responded to past adverse experiences to help them cope with the PD caregiving situation. Moore et al. (2011) also found that prior trauma was positively associated with positive psychological changes and growth-ful development for caregivers of family members with advanced liver cancer. Furthermore, Carter et al. (2010) found older PD caregivers were more readily able to find benefits in caregiving compared to their younger counterparts because older caregivers were more likely to have experienced past adversities. As a result of these adversities, it was

proposed that this shaped the older caregivers' ability to find the benefits of caregiving.

These previous studies findings appear consistent with the present study findings.

7.1.4.5 Sub-theme 4e: Support Groups. This sub-theme indicated that PD support groups appeared to be conducive to positive psychological changes and growth-ful development, which is consistent with numerous caregiving studies across populations including stroke caregivers (Hallam & Morris, 2013), HIV caregivers (e.g., McCausland & Pakenham, 2003) cancer caregivers (e.g., Kim, Schulz, & Carver, 2007; Manne et al., 2004; Weiss, 2004) and dementia caregivers (e.g., Leipold et al., 2008; Liew et al., 2010; Yap et al., 2010). These studies found a positive relationship between each self-perceived positive psychological change and growth-ful change, and support group attendance.

In the present study, many loved ones stated that when attending PD support groups, they are exposed to other persons with PD and their loved ones who share a similar fate. Blanchard et al. (2009) also found support group attendance prevented adult-children providing care to their person with PD from "hiding behind the reality of the disease" (p. 74). Similarly, in the present study many participants stated that even though support groups were initially confronting because they saw the negative effects of the disease in more advanced stages, the groups provided an opportunity for the loved ones to compare their personal circumstances with others who were in similar situations. For example, they compared the way their person with PD was adjusting to the disease, or the progression rate of the disease compared to other persons with PD at the group. Hence, this sub-theme indicated that PD support groups appeared to be fertile ground for loved ones to make downward comparisons. Seemingly as a result of these downward social comparisons, these loved ones were reminded that things could be worse, and they came to recognise that there were many positives in their lives, which resulted in a sense of gratitude and appreciation for their personal circumstances.

Some loved ones in the present study described that they had compared themselves with other loved ones at the group, and concluded that they had more support from their person with PD and/or family support than other loved ones. Through this process of social comparison, these participants grew to appreciate their person with PD and/or their family more since the presence of PD in their lives. As previously mentioned, loved ones providing care described a new found appreciation for their person with PD with regards to the way he or she handled the disease. Through this cognitive process, loved ones came to perceive their person with PD in a different light, and served as a reminder of that person's positive personal qualities, such as strength, courage and determination. Moreover, the exposure to others dealing with the negative implications of the disease helped the loved ones providing care to recognise that others too were dealing with the adversities of PD, and that life's challenges and personal failures are simply part of human suffering.

Similar to the Hodgson et al. (2004) findings, many loved ones providing care for PWP stated that the PD support groups were an important resource, and a valuable way of acquiring knowledge and accessing up-to-date information and support. This, in turn, contributed to personal growth such as becoming more knowledgeable. In addition, this sub-theme also demonstrated that the support groups provided an opportunity for altruism, similar to findings that surfaced in dementia studies (Sanders, 2005; Netto, 2010). Altruism manifested in loved ones sharing their caregiving knowledge, experience and expertise to help others at the groups who were also on the caregiving journey. Expression of altruism can be considered as a positive aspect of the PD experience. Lastly, this sub-theme also indicated that PD support groups helped loved ones providing care feel less socially isolated. One PD study found support groups buffered feelings of isolation in caregivers (McRae et al., 2009). Sanders (2005) found that dementia caregivers who were socially isolated reported lower scores on personal growth associated with caregiving.

7.1.4.6 Sub-theme 4f: Developmental stage of life and relationship. This sub-theme contained some of the examples of positive psychological changes (e.g. increased tolerance of existentialist ambivalence), growth-ful development (e.g., becoming more patient) and relationship growth, (e.g., becoming closer to spouse, less arguments) better accounted for by the participants' developmental stage of life and/or the developmental stage of their relationship with person with PD as opposed to the PD caregiving experience per se. This generational factor was considered pertinent due to a predominant geriatric population of PD sufferers and participants of this research, as PD typically affects people in later stages of life as the disease slowly progresses. However, Leipold (2008) argues that personal growth is not attributed to a generational bias, but rather as a result of the caregiving experience for a family member affected with dementia. More research in PD caregiving is warranted to extrapolate generational bias from outcomes of experience.

Nonetheless, Carter et al. (2010) found that the ability to find positive meaning associated with PD caregiving was lower in younger PD caregivers (aged 40 – 55) than older counterparts (aged 70 and over). Carter et al. concluded that there is an increased likelihood for older spouses having experienced past adversities, such as personal ill-health or the ill-health of family members or friends, and in turn influences their ability to find positives and rewards in caregiving. Therefore in the present study, older loved ones may have had lower expectations of both their spouse and the quality of the relationship due to increasing age, and more specifically the duration of their relationship or marriage. Similarly, this could explain why older caregivers report more satisfaction associated with PD caregiving in contrast to the younger caregiver who may have had higher expectations for their relationship considering their stage of life.

Middle-aged spouses who assume the role of the primary informal caregiver often have to leave work, or take early retirement before they were ready to do so (Carter et al.,

2010). In these instances an individual may feel unfulfilled, as they may consider themselves as “being in the prime of their life” and yet to achieve a sense of self-confidence or self-actualisation at work (p. 724). Therefore, leaving work early may result in feelings of dissatisfaction and a sense of un-fulfilment, which may impede the ability to find a silver-lining and thus result in diminished life satisfaction. That is, it may block the ability for positive psychological change and growth-ful developments in younger caregivers of persons with PD. On the other hand, younger carers may be more cognitively/psychologically flexible and thus better able to adjust, or there may be some who are happy to retire early; these could represent a cohort of the younger carers who are more accepting of the change in role. Again, further research is warranted.

7.1.5 Master theme 5: Lacking in positive changes and growth-ful development.

This master theme illustrated when adaptive responses (positive psychological experiences and growth-ful development) to adversities were not perceived or reported by participants.

7.1.5.1 Sub-theme 5a: No positives, only negative. Some participants could only identify negative experiences associated with the caregiving role. This finding is consistent with findings cited from previous studies focused on adult-children who provide care to a parent with dementia and PD (Habermann et al., 2013), Singaporean family caregivers (Tan et al., 2012), persons with PD (Chiong-Rivero et al., 2011) and family members providing care for persons with dementia (Netto et al., 2009; Sanders, 2005), whereby a proportion of their samples also reported no benefits, only losses and strains. A common theme in these studies for carers who could only recall strains and losses was a lack of assistance and support for these carers (Sanders, 2005), as replicated in this study.

7.1.5.2 Sub-theme 5b: PD doesn't interfere with our lives or relationship. This sub-theme indicated that some loved ones did not perceive that PD had interfered with their lives, and they were unable to recall any positive or negative changes. Further, the present study

revealed that predominantly wives providing care for a husband with PD were unable to report any personal growth as a result of the caregiving situation. This could be explained by the wives not feeling tested by the caregiving situation, and therefore it had not created any opportunities for skills development and personal growth. Peacock et al. (2010) and Sanders and McFarland (2002) found that husbands report the highest percentage of both strains and gains associated with providing care for a loved one with dementia, compared to wife counterparts. Sanders and McFarland suggest that husbands were less skilled in caregiving than wife counterparts, and therefore had room for growth-ful development and skills development. This suggestion appears consistent with the present study findings as well as the recent longitudinal study (Danhauer et al., 2015) investigating the trajectory of PTG and individual differences in breast cancer survivors. Findings revealed that women who reported lowest levels of PTG, also reported lowest levels of illness intrusiveness (in other words, they believed that their illness had not interfered with their lives in terms of work, recreation, relationship with spouse and family) active-adaptive coping and depression. These women were older, reported less financial strain, and also reported higher levels of social support. Findings suggest that the cancer diagnosis was not as disruptive to their lives of the women in this trajectory and therefore required less coping compared to the other group-based trajectories. Furthermore, findings suggest that social support may provide a buffer that prevents breast cancer from being disruptive enough to catalyse positive psychological changes and growth-ful development. Similarly in the present study, analysis revealed that those who did not report personal growth were also older, reported feeling supported by family and friends, had experience in caregiving (either professional and/or personal), and did not perceive PD had interfered with their lives, neither positively or negatively. These factors appear to play a role in this theme – lacking in growth-ful development.

It appeared that factors associated with the nature of PD could account for the sub-theme 5b: *PD hasn't interfered with our lives or relationship*. The slow and gradual progression of PD combined with the medication's positive effects during the early stages of the disease essentially masked the PD symptoms, which seemingly created a false sense of normalcy during the early-to-mid stages of the disease. Loved ones, whose person with PD was in the disease's early-to-middle stages, were required to provide little to no assistance to their person with PD because the symptoms were minimal and the person with PD was able to maintain normal functioning. Consequently, there was nil to minimal impact of PD on their lives.

Another plausible explanation for the theme *lacking in self-perceived psychological changes and growth-ful development* could be that loved ones did not have sufficient knowledge and understanding about PD and implications on their future. Hence, loved ones may have remained largely unaware of the possible negative impacts that PD would have on their lives as the disease progressed. Several other previous PD caregiving studies (Hodgson et al., 2004; K. S. Kim et al., 2007; McLaughlin et al., 2011; Tan et al., 2012; Wressle et al., 2007) also found that lack of information about PD and what to expect was commonly reported by loved ones who complained that the information was vague and unforthcoming. However, Dyck (2009) acknowledged that the difficulty for health professionals providing specific information about what the future may hold resulted from the unique and unpredictable nature of PD.

In contrast to loved ones who actively sought information in order to search for comprehensibility to make sense of the diagnosis and gain knowledge about the disease to restore a sense of control over the outcome of the disease, other loved ones employed avoidance coping mechanisms by actively avoiding learning about PD. For example, loved ones avoided attending support groups for the fear of being confronted by PD when seeing

others in the later stages of the disease. In addition, some loved ones in the present study were encouraged by their specialist not to research PD, or essentially acquire any knowledge about PD at the time of diagnosis. Hence, these loved ones were protected from the knowledge of the disease's negative effects.

The absence of relationship growth may be associated with the perceived quality of pre-PD relationships between loved ones providing care and persons with PD, as reported by the caregiver. This is evidenced by participants who reported no change in relationships because their relationships were very good to begin with. Similar factors may explain why some loved ones providing care did not report feeling closer to their families as a result of the PD caregiving experience. That is, some participants reported no change in their family relationships because they were already of a good quality before the PD caregiving experience, and therefore they perceived no room for improvement. Further, for those loved ones undertaking the caregiving role alone, there may be limited or no opportunity to bond or unify with other family members as a result of sharing the burdens and joys of caregiving. Therefore, strengthening family relationships may be more obvious for caregivers who have other relatives actively involved in the care of their person with PD. Now that the present study findings have been discussed in relation to the existing caregiving literature, psychological theoretical frameworks will help further explain the present study's master themes.

7.2 Interpretation of Themes Using Growth Models

Within the previous section, participant responses were presented according to researcher interpretations within the context of existing caregiving literature. The master themes (and sub-themes therein) will now be explained by utilising the psychological theoretical frameworks of the revised meaning making model (Park, 2010), the Adversity-Activated Development theory (AAD) (Papadopoulos, 2007), and the post-traumatic growth

theory (PTG) (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010) as well as other relevant psychological theories. In doing so the present study builds upon previous studies because it presents a deeper interpretation of findings. Previous caregiving studies (Blanchard et al., 2009; Habermann et al., 2013; Hodgson et al., 2004; Netto et al., 2009; Sanders, 2005; Tan et al., 2012) did not use common growth theories to interpret their findings, which makes the present study novel and therefore a major contribution to the PD caregiving literature.

A brief summary of the key conceptualisations of positive change and growth-ful development as following exposure to adversity (outlined in Chapter two) are first revisited as a refresher to the reader, and to allow the reader to understand how the researcher has interpreted findings using these influential theoretical models of growth. The starting point of positive change and growth-ful development begins the appraisal of a potentially stressful situation as indeed stressful. This appraisal triggers various types of meaning-making processes (e.g., deliberate rumination, searching significance, and various cognitive and emotional processes) in an effort to reduce the discrepancy between expectation and lived experience related to this stressful situation. This produces outcomes of the meaning-making process such as the perception of personal growth, a type of meaning-made (Park, 2010; Calhoun, Cann & Tedeschi, 2010; Papadopoulos 2007). The numerous types of meaning-making processes and numerous types of meanings-made were represented in the themes and sub-themes formulated from participants' responses, which is explored in more detail.

7.2.1 Positive psychological changes.

7.2.1.1 Sub-theme 1a: “Making the most of it,” through re-evaluation and reprioritisation. In accordance with the revised meaning making model, the type of meaning-making process encapsulated in this sub-theme was *deliberate rumination* and the type of meaning-making outcomes of this process were *changed goals, changed values* and

changed beliefs (Park, 2010). These processes of meaning-making or making sense are explored as follows. It was clearly evident that caregivers were initially shocked and worried upon receiving news of their loved ones' diagnosis. Both the revised meaning-making model (Park, 2010) and PTG (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010) explain this shock as an automatic and intrusive rumination in response to the significantly stressful event. In line with these models, this finding supports the present study's underlying theoretical conceptualisations (presented in chapter two), as not only do loved ones experience adversity (the shock of PD diagnosis, as postulated by conceptualisation one) but this adversity is perceived as significant enough to cause a change to one's global meaning through a specific meaning-making process, in this case, deliberate rumination. This, in turn, leads to positive psychological change and/or growth-ful development (as postulated by conceptualisation two).

Through the cognitive process of deliberate rumination and thoughtful life reflection (meaning-making process), loved ones came to realise what was truly important or of value to them (meaning-made). Subsequently, these participants engaged in a process of life plan and goal reprioritisation in accordance with their reaffirmed values. This was evidenced by participants' decisions to either abandon goals that were no longer attainable, to substitute for alternative goals, or in many instances to bring long-term goals forward. For example, there were numerous instances where the loved ones reprioritised their relationships with their persons with PD. Subsequently, these loved ones revised their behaviour in accordance with this reprioritisation by choosing to engage in more meaningful pursuits and interests with their persons with PD (e.g., deciding to travel overseas whilst their loved one with PD was still physically able). The PD diagnosis, and other adversities presented by the PD caregiving experience (e.g., witnessing their person with PD deteriorate), served to either reaffirm pre-existing beliefs or change beliefs about life, such as "time is short" or "life is

fragile.” In accordance with the revised meaning-making model, this heightened appreciation that “life is short” is an example of a meaning-making outcome as a product of the meaning-making process of deliberate rumination.

An alternative conceptualisation of this particular finding found within this sub-theme is provided by AAD as *new ways of thinking and being* (Papadopoulos, 2007). Also, this sub-theme was deemed by the researcher as most aptly belonging to two of the five PTG domains of positive change in the aftermath of adversity, including *increased appreciation for life and refined sense of priorities* and *existential and spiritual development* (Tedeschi & Calhoun, 2004).

In a similar vein, existential theory can be applied to this sub-theme to explain an *awakening experience*. That is, a confrontation with death or shortened life arouses anxiety as well as an opportunity to vastly enrich one’s life (Yalom, 2008). Yalom asserts that it takes something like the diagnosis of an irreversible, incurable disease – PD in this instance – to awaken a person from an *everyday mode of existence* to an *ontological mode of existence*. In an ontological mode, individuals become less concerned about trivialities and preoccupations of everydayness, such as concerns about physical appearance, money, possessions and status. That is, individuals become more aware of “being” in terms of existence and mortality (Yalom, 2008, p. 41). Though differing slightly in the way processes of change are explained, all these theories serve to illustrate how positive psychological experiences and growth-ful developments occur in the face of adversity resulting from the PD caregiving experience through an existentialist re-evaluation.

7.2.1.2 Sub-theme 1b: Finding meaning in caregiving through benefit finding and meaning-making. In accordance with the revised meaning-making model this sub-theme serves to illustrate how the meaning-making coping process of *searching for significance* results in types of meanings made of *restored or changed sense of meaning in life*. This

model proposes that through these meaning-making efforts, loved ones are able to regain a sense of usefulness, purpose and worthiness (Park, 2010). Alternatively, this sub-theme can be conceptualised in accordance with PTG theory as the *identification of new possibilities or sense of purpose* (Tedeschi & Calhoun, 2004). Either way, similar to the previous sub-theme, this arguably encapsulates an adaptive coping strategy as it increased the loved ones' abilities to cope with the caregiving situation.

7.2.1.3 Sub-theme 1c: "We're the lucky ones," greater sense of gratitude through social comparison. This sub-theme clearly demonstrates that loved ones employed the cognitive coping strategy, *downward social comparison* (Taylor, 1983), which is considered a natural and adaptive coping mechanism (Park, 2010). This meaning-making process involved making downward social comparisons to (perceived) less fortunate others, such as friends, family members or the wider community diagnosed with conditions such as an inoperable brain tumour, dementia or terminal cancer. As a result of downward social comparison, these loved ones arrived at the belief that the diagnosis could be worse, and they described a sense of gratitude and appreciation that they were diagnosed with PD and not something worse (e.g., brain tumour). Through this cognitive process, the initial appraisal of the PD diagnosis was transformed from threatening to more acceptable, and the diagnosis was rendered less noxious than the initial appraisal. The revised meaning-making model explains this as *retribution, a type of meaning-made* (Park, 2010). Once again, this sub-theme supports the assumption that the PD diagnosis has potential to be seismic enough to shatter the assumptive world and create changes in global meaning, supporting the underlying theoretical assumptions of this present study as presented in Chapter Two.

For some, the PD diagnosis challenged beliefs about fairness, resulting in the diagnosis being appraised as unjust. After the initial appraisal, individuals determine either a fit or a discrepancy between the PD diagnosis and their global meaning. If the loved one

perceives that there is a discrepancy (e.g., beliefs about justice, such as what is considered fair), this is thought to create a heightened sense of anxiety, distress, and/or a sense of meaninglessness, which initiates meaning-making coping processes. That is, intrusive rumination is transformed to more deliberate rumination in order to reduce the discrepancy between appraised meaning and global meaning to alleviate the distress, uncertainty and sense of loss or meaninglessness (Park, 2010) associated with the PD diagnosis, and ultimately for successful adjustment to the PD diagnosis.

This finding also supports the assumption that loved ones' experiences of positive psychological change are adaptive coping strategies due to the exposure to adversity (PD diagnosis), and thus consistent with the meaning-making model that humans highly motivated to maintain self-regard, and a sense of control and esteem. When self-regard is threatened (e.g., at the time of diagnosis), cognitive processes such as downward social comparisons are employed in order to maintain positive illusions or beliefs about the self and the world (e.g., Filipp, 2001; Park, 2009; Taylor, 1983). This adaptive coping process was demonstrated in the participants' accounts that suggested they were lucky compared to others diagnosed with other life-threatening conditions. Hence, the loved one may have regained a sense of control and fairness, and ultimately a restored sense of positive self-esteem regard by believing they were more advantaged compared to others.

This reattribution or causal understanding of the PD diagnosis is likely to be more consistent with pre-existing beliefs, goals and desires. For example, a person may have initially thought that having a loved one diagnosed is unfair, which in turn challenges beliefs about justice, but by comparing the PD diagnosis they may come to believe that it could be worse, and therefore maintain a belief that life is indeed fair towards them. The revised meaning-making model proposes that this would help a loved one to accept and ultimately adjust to the PD diagnosis. This sub-theme is consistent with PTG theory that proposes one

of the five domains as *increased appreciation and gratitude for life* following a traumatic or highly stressful event (Tedeschi & Calhoun, 2004). Alternatively, this sub-theme is consistent with the AAD's *new ways of thinking* and *new ways of being* (Papadopoulos, 2007).

7.2.1.4 Subtheme 1d: “Touched by Parkinson’s,” the desire to positively contribute to those affected by PD. The sub-theme could be explained by the revised meaning-making model (Park, 2010) as changed beliefs, goals and sense of purpose, which manifested in engagement and involvement in the PD community, raising funds for PD, and/or partaking in PD research. This model explains that the loss of goals, belief and sense of meaning causes an existentialist crisis and results in adapting the process of growth-ful development (Park, 2010).

An alternative conceptualisation of this particular finding of increased respect for the finiteness of life, found within this sub-theme, is provided by AAD as not only *new ways of thinking and being, but new opportunities* (Papadopoulos, 2007). Also, this sub-theme was deemed by the researcher as most aptly belonging to the *identification of new possibilities and refined priorities* (Tedeschi & Calhoun, 2004) which is one of the five positive outcomes in the aftermath of an individual struggling to make sense of having a loved one diagnosed with PD. However, as previously outlined in Chapter Two, shattering fundamental assumptions and beliefs is the keystone to PTG theory’s theoretical framework (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010). In contrast, the revised meaning-making model (Park, 2010) makes global meaning (shattering of beliefs, loss of goals and meaning) initiate meaning-making processes for positive change and growth-ful development. This sub-theme supports the study’s premise, which is aligned with the revised meaning-making model.

Existentialists like Yalom (2008) conceptualise the desire to contribute positively to others' lives before their own life ends as the "rippling effect" (Yalom, 2008, p.61). The rippling effect occurs when an individual leaves something of life's experience behind. Examples of rippling are when an individual leaves pieces of wisdom, guidance, or brings comfort to others, which in turn live on through others. According to Yalom, the rippling effect provides an individual with a powerful framework for their life's meaning, to be of value to others, and is therefore a way of meeting existential needs.

7.2.1.5 Sub-theme 1e: "Just got to accept it," greater acceptance of the ambiguous nature of the PD and life in general. According to the revised meaning-making model, this sub-theme represents an example of the meaning-making coping processes of *searching for significance*, the meaning-making outcome being a greater sense of acceptance. By positively reframing the caregiving situation as an opportunity to change their life perspective and letting go of control, participants were able to avoid excessive rumination about past losses. Whilst the meaning-making model views acceptance as an outcome of meaning-making processes, PTG theory views acceptance as a precursor to positive psychological change and growth-ful development (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010). Present study findings indicate that there were varying levels of acceptance amongst participants, and therefore findings appear more consistent with PTG theory.

7.2.2 Growth-ful development associated with PD caregiving. The revised meaning-model (Park, 2010) conceptualised growth-ful development pertaining to personal growth as *perceptions of growth or positive life changes* (see Figure 1). Park (2010) explains self-perceived personal growth as an outcome of meaning-making coping processes such as *searching for significance* in the caregiving situation. Examples of searching for significance are *benefit-finding*, which involves finding the benefits in a situation as a way to reduce

distress (Affleck & Tennen, 1996) or *positive reappraisal*, which involves reframing a situation and perceiving it in a positive light. Similar to sense-making, benefit-finding is a form of cognitive restructuring and reappraisal. Sense-making is concerned with the comprehensibility of an event (sense) compared to benefit-finding or positive reappraisal, which is concerned with the event's significance (benefit) (Janoff-Bulman & Yopyk, 2004). Through employing the cognitive coping strategy of searching for significance (i.e., benefit finding and positive reappraisal), loved ones came to perceive their PD caregiving situation as an opportunity for personal growth as evidenced in this theme and sub-themes.

Personal growth as a result of caregiving can be explained by AAD theory (Papadopoulos, 2007) as a response to the exposure to caregiving demands associated with having a loved one diagnosed with PD, or during the caregiving situation. To reiterate from Chapter Two, AAD can support this theme because exposure to adversity during the PD caregiving situation challenges the caregivers' previous understandings, beliefs, identity and expectations (of themselves, the world, others, and their relationships). AAD theory explains that it is the exposure to the caregiving demands that pushes the caregivers to their limits and beyond, and in reaching or exceeding their limits it opens the caregivers to transformation through new ways of being and thinking, and to new opportunities "beyond what was previously planned or even imagined" (Papadopoulos, 2007, p. 308).

Adversity-activated development theory (Papadopoulos, 2007) could explain self-reported interpersonal skills (e.g., becoming more patient, more capable, more flexible and adaptable) as "new ways of being," as a result of the caregiving situation (p. 308). For example, predominantly bereaved caregivers and loved ones providing care during advanced stages of the disease stated that they felt more capable and confident. AAD theory (Papadopoulos, 2007) would explain this as loved ones being pushed to their limits and beyond during the caregiving situation. For example, loved ones providing care stated that

they were required to step up and assume tasks and responsibilities previously performed by their person with PD. Initially this challenged the beliefs and expectations of themselves, but through successfully accomplishing these tasks and responsibilities they acquired a sense of personal strength and accomplishment as they perceived they had surpassed their previous level of coping and expectation, and believed that they could handle more than they previously imagined. Similar to previous dementia caregiving studies (Netto et al., 2009; Sanders, 2005), the present study found loved ones providing care (especially long-term caregivers and bereaved caregivers) reported skills development and improved coping skills, including the perception that they were “better at handling a crisis.”

7.2.3 Contextual experience. There appeared to be contextual factors that influenced outcomes such as self-perceived positive psychological changes and growthful development in response to the PD diagnosis and the PD caregiving situation. Findings suggested that there were socio-relational factors as well as personal factors that were relevant in positive psychological changes and growthful development in the loved ones providing care.

7.2.3.1 Socio-relational factors. PTG theory (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010), unlike the revised meaning-making model (Park, 2010) and ADD theory (Papadopoulos, 2007) place emphasis on the socio-cultural context and can explain this theme, and specifically sub-themes 5a: *Meaning-made at the time of diagnosis*, 5b: *PwP’s experience*, 5c: *Quality of pre-PD relationship*, and 5e: *Support groups*, most comprehensively. PTG theory specifies that the social environment can facilitate an individual’s engagement in deliberate rumination (contemplating changes brought on by having a loved one with PD), and consequently produce positive psychological changes and psychological development. PTG theory maintains that the contemplation of changes brought on by traumatic experiences (deliberate rumination) is an emotionally painful and

confronting process. Yet deliberate rumination in an accepting, comforting social environment, particularly with those who too have shared similar experiences can help one to continue the cognitive processing without becoming overcome with negative feelings and thoughts (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010).

Sub-theme 5e: *Support groups* clearly demonstrated that PD support groups provided caregivers with the opportunity to share experiences, perspectives, beliefs and knowledge to discuss their personal circumstances, and receive and provide emotional support. PTG theory states that PD support groups are fertile ground for the activation of cognitive (e.g., deliberate rumination) and emotional (e.g., delving into and express emotions) processes necessary for positive psychological changes and growth-ful development (Tedeschi & Calhoun, 1996, 2004). PTG explains that social support, especially from others who share the same fate (other caregivers at the support groups), is a predictor of positive psychological change and growth-ful development. Cognitive processing of the adversities relating to the caregiving situation is aided by self-disclosure, (including talking about thoughts, feelings and experiences) to empathetic others who too have “been there” in mutually supportive social environments can be crucial in determining the degree of willingness for those also affected by similar adverse events, and to incorporate new perspectives or schemas (Antoni et al., 2001; Tedeschi & Calhoun, 1996, 2004). It is through these socio-cognitive-emotive processes that caregivers may receive validation, or feedback, and most relevant to the present study, develop alternative and more positive ways of looking at the situation and new ways of being (Tedeschi & Calhoun, 2004). PTG would also consider PD support groups as an opportunity to expose loved ones providing care to positive role-models who may express positive beliefs and emulate positive change and growth-ful development associated with the PD caregiving situation. That is, modelling the ways of thinking and being that can be satisfying and even improved as a result of exposure to the caregiving situation’s adversities.

Weiss (2004) describes this as a *growth contagion phenomenon*, and postulates that the exposure to another individual who makes positive interpretations or appraisals of any given situation experience is “contagious” because there is a transmission of self-perceived positive psychological change and growth-ful development between marital partners. This phenomenon is consistent with present study findings (sub-theme 4b: *Persons with PD experience* and sub-theme 4c: *Quality of relationship*).

7.2.3.2 Personal factors. The sub-theme 4d: *Past and/or current adverse experiences* suggested that loved ones called upon past adverse experiences that had assisted them in the PD caregiving situation. This finding is inconsistent with PTG theory (Tedeschi & Calhoun, 2004), but consistent with the conceptual model of life crisis and personal growth (Schaefer & Moos, 2001) that posits prior crisis experience as a significant determinant of positive outcomes in adversity.

The sub-theme 4f: *Developmental stage of life and relationship* suggested that the participants’ developmental stage of life and/or the developmental stage of their relationship with PD sufferer, especially in spousal relationships, were relevant in self-perceived positive change and growth-ful development. Whilst it can be argued that positive psychological change and growth-ful development are better accounted for by stage of life and relationship, it was evident that the caregiving situation provided caregivers with an opportunity to fulfil existential needs such as finding meaning (sub-theme 1b: *“Finding meaning in caregiving,” through benefit finding and positive reappraisal*).

Cohen’s (2001) theory of developmental needs for human potential in older adults explains the caregiving situation as providing loved ones of persons with PD with opportunities to fulfil developmental needs for human potential. Cohen proposes that there are four human potential stages for later life that include: (1) mid-life re-evaluation (occurs during 40s-50s), (2) liberation (occurs during mid-50s to 70s), (3) summing up (occurs

during late 60s into 90s), and (4) encore stage (occurs during late 70s to end of life). The mid-life re-evaluation stage is characterised by a process of life-reflection and contemplation of a person's life with a desire to make their life more gratifying or meaningful. This stage may be prompted by a "mid-life crisis" when an individual has a sense that their life is becoming meaningless. In the present study, many participants reported that the knowledge of PD and impending restrictions on their quality of life, prompted them to re-evaluate and reprioritise their lives, and allowed them to re-connect with values and take committed action in accordance to these personal values.

The second stage, liberation, is characterised by a personal sense of freedom that comes both psychologically from within (e.g., feeling more confident in their own being, and less inhibited compared to earlier developmental stages) as well as externally (e.g., retirement, or no longer having to take such an active role in parental responsibilities). According to Cohen (2001), when an individual experiences freedom from previous responsibilities they are rewarded with the time to try something new. In this study, some participants aged between 50 and 65 years stated that they re-evaluated their financial and parental obligations and, in light of the PD diagnosis, they went travelling sooner than they would have done without the presence of PD in their lives. However, it is likely to be a combination of the two, freedom from parental and financial responsibilities as well as a PD diagnosis in their 50s.

The third summing up stage is characterised by an individual's greater sense of urgency and profound desire to find larger meaning in the story of his or her life as it nears an end. This stage involves life reflection, summing-up and giving back. Likened to what Yalom (2008) describes as the rippling effect, at this stage individuals may experience themselves as keepers of the culture and have a desire to contribute to others (e.g., volunteerism, community activism and other activities of giving back) in terms of sharing

knowledge, wisdom or wealth that they have accrued during their life. This “summing-up process also helps to realise unfulfilled dreams and unfinished business, which can lead to a new creative burst to complete a missing chapter in one's life story” (p.53). The fourth and final encore stage involves continuation, reflection, and celebration. It is characterised by the “desire to make a final statement”, that is, “to affirm life and celebrate one’s place in the family, community, and in the spiritual realm” (p.54).

Therefore, sub-themes 1b: *Finding meaning through caregiving*, 1c: *Touched by PD, the desire to contribute positively* and 4e: *Support groups*) demonstrate that the caregiving situation provided opportunities to revise beliefs and goals and engage in activities (e.g., expressing altruism and sharing knowledge at support groups) that may fulfil existential needs for human potential. For instance, many loved ones reported that after being touched by PD, they had a desire to contribute positively to others (at support groups and within the PD community) by sharing their experience and knowledge of their PD caregiving experience at a community level. This involvement in the PD community provided an opportunity for these individual to positively transform and work towards fulfilling or actualising needs for human potential during the later phases of their life.

Present study findings also revealed that long-term caregivers, or older caregivers in most cases, reported more positive experiences and growth-ful development than younger caregivers. Cohen (2001) explains this by differing developmental stages of life. Cohen (2001) proposes that the later stages of adult life usually involve a transition to retirement. Whereby goals of work performance and achievement typically shift to maintaining valued relationships (e.g., spending time with family/caring for family) and finding goals that give one a sense of fulfilment and purpose within relationships as opposed to work pursuits. Cohen’s theory could explain this finding as older caregivers place more emphasis and become more invested (and seek to find meaning and fulfilment) in relationships with

significant others, than younger counterparts. Therefore, enhanced personal and relationship growth-ful development may arise from changes in developmental needs and motivations for later stages in life rather than the presence of PD and the PD caregiving situation.

7.2.4 Lacking in positive changes and growth-ful developments. To reiterate, in contrast to those who reported positive changes in perspectives on living, and personal and relationship growth, there were some loved ones providing care who could only identify negative aspects and loss associated with PD, as evidenced in sub-theme 5a: *No positives, only negatives*. There were other participants who stated that there had been no positive or negatives changes in their lives since their loved one had been diagnosed with PD, as evidenced in the sub-theme 5b: *PD doesn't interfere with our lives or relationship*.

7.2.4.1 Sub-theme 5a: No positives, only negatives. This sub-theme could be explained by these loved ones being too overwhelmed to experience positive psychological changes and growth-ful development. It has been found that the exposure to overwhelming and extreme conditions reduces the likelihood of perceived growth-ful development (Papadopoulos, 2007; Park, 2010; Tedeschi & Calhoun, 2004). Rather, the revised meaning-making model (Park, 2010) and PTG theory (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010) postulate that an optimum environment, one of perceived moderate stress as opposed to low stress or high times of stress, is most conducive for growth-related change. Moreover, in the present study these caregivers also described feeling socially isolated and unsupported by their person with PD. As mentioned above, this is consistent with PTG theory, which proposes that social support plays an important role in positive outcomes and growth-ful development.

7.2.4.2 Sub-theme 5b: PD doesn't interfere with our lives or relationship. This sub-theme can be explained by participants not perceiving that they had been exposed to any appraised challenging or stressful caregiving events or situations. In other words, the

presence of PD and events that occur during the PD caregiving situation (e.g., PD diagnosis, attended to caregiving tasks) may not have been initially appraised as seismic or stressful enough to activate meaning-making processes necessary for self-perceived positive changes and growth-ful development (Papadopoulos, 2007; Park, 2010; Tedeschi & Calhoun, 2004; Cann, Calhoun & Tedeschi, 2010). Moreover, there was no “is-ought” discrepancy between the loved ones’ initial appraised meaning of the PD diagnosis and the loved ones’ global meaning. In short, there was not enough perceived strain to report perceived gain.

Loved ones who did not perceive that they had grown personally since the presence of PD in their lives were the wives of husbands with PD. They stated that there had been no change in their relationship structure, dynamics or role responsibilities compared to the pre-PD relationship. These wives stated that they had always assumed all, or the majority, of the household tasks prior to their husband being affected by PD. Therefore, they perceived that they had not been called upon to do anything differently in terms of role responsibilities, and appeared to view caregiving as a continuation of their relationship with their husband.

The theoretical models of AAD, PTG and the revised meaning-making model would explain the sub-theme 5b: PD hadn’t interfered with the loved ones’ lives, by wives not perceiving that the caregiving situation had tested or challenged them enough to activate meaning-making processes necessary for growth-ful development. Most specifically, this theme is consistent the theoretical model of PTG that illustrates that an event can challenge some peoples’ assumptive beliefs, whilst others can readily incorporate the event(s) into their assumptive beliefs without disruption to their personal goals, narratives or worldview, thus will not engage in processes the ostensibly can lead to PTG, but report positive outcomes such life satisfaction and well-being (Calhoun, Cann & Tedeschi. 2010). Analysis of these individuals’ accounts revealed that they seemed generally satisfied with their lives, which is consistent with the most recent model of PTG. Moreover, AAD theory may explain this

finding as a *neutral response* (Papadopoulos, 2007) to the caregiving situation, or in other words, one of resilience. These participants did not report any negative or positive psychological changes and growth-ful development, and may have simply adjusted to the PD caregiving situation. Similarly, the meaning-making model would suggest that these loved ones might not have considered a discrepancy existed between their personal resources, knowledge and skills, and the demands of the caregiving situation. Thus, minimal stress or distress is experienced, and in turn, meaning-making coping processes are not required to alleviate any distress. Again, not enough strain to perceive any gain. In addition, it was also observed in the present study that many of the participants who stated that PD hadn't interfered with their lives, had previous informal and formal (e.g., nurse) caregiving experience. A possible explanation for this finding could be that these individuals had high self-efficacy and confidence in their abilities, and therefore did not feel challenged by events or experiences that occurred during the caregiving situation.

As previously mentioned, the meaning-made about PD at the time of diagnosis appeared to be relevant, and certain contextual factors appeared to be associated with positive changes or lacking in positive changes. These include limited knowledge and understanding of the seriousness and debilitating nature of the disease and its effects, compounded by the effects of the medication masking the symptoms that seemingly created a false sense of normalcy. Receiving optimistic messages (e.g., not life-threatening, more likely to die of other causes) conveyed at the time of diagnosis may have further compounded this situation. Each theory could explain that not having adequate knowledge of the disease may be detrimental, rather than beneficial, because it may prevent meaning-making process activation necessary for growth-ful development. In other words, if a loved one is not provided with accurate and complete knowledge about the imminent negative impacts of PD on their future, they are less likely to perceive the diagnosis of PD as stressful or distressing.

Therefore, they are less likely to engage in cognitive processes, such as deliberate rumination and life reflection, and subsequently block an awakening experience that would result in self-positive psychological changes and growth-ful development. This may explain why some did not make positive changes to their lives shortly after receiving the diagnosis. Existential theory by Yalom (2008) could explain this finding as the loved ones remaining in everyday existence rather than moving to an ontological existence (e.g., pondering existential questions such as meaning/purpose in life), which is conducive to positive psychological changes and growth-ful developments.

As previously mentioned, another plausible explanation for the theme 5: *Lacking in self-perceived psychological changes and growth-ful development* could be that loved ones were indeed aware of the seriousness and debilitating nature of PD, and the possible implications at the time of diagnosis. However, they may have selectively attended to this information and only heard what they wanted to hear and suppressed (or repressed through denial) the more threatening and stressful information about the nature of PD.

Psychoanalytic theory would explain this cognitive process as *omission*, which involves leaving certain details out to tailor a story. This is an attempt to make the effects or results of an action or event (e.g., having a loved one diagnosed with PD) appear to be less threatening to one's global meaning than it may actually be. Similarly, minimisation may have been employed, which involves admitting the fact (e.g., the diagnosis) but denying its seriousness and impacts on life.

Another plausible explanation for the theme 4: *Lacking in positive psychological changes and growth-ful development* could be that loved ones had not fully accepted the PD diagnosis and the imminent implications the disease may have on their lives. Rather, they employed cognitive avoidance coping defence mechanisms such as denial, minimisation, distraction, and suppression of intrusive thoughts or memories. Examples of these defence

mechanisms were evidenced in participant accounts, for example, suppression of intrusive thoughts and memories (e.g., avoided thinking about the possible implications of PD and the future, denial, and distraction). These defence mechanisms appear to manifest in loved ones' accounts that pertained to largely denying the implications PD could have on their lives. They carried on as normal by becoming preoccupied with everyday routines and control strategies, rather than accepting the disease and long-term negative outcomes.

Denial and avoidance coping are maladaptive ways of alleviating the unwanted private experience and emotional discomfort (Hayes et al., 1999; Wilson & Murrell, 2004) that may accompany a PD diagnosis. Denial and avoidance coping have been found to block self-development because they impede or interfere with acceptance of an adverse, trauma or stressful life event (Park, 2010; Tedeschi & Calhoun, 2004), and with engagement and immersion in meaningful life activities (Kashdan, Barrios, Forsyth, & Steger, 2006; Kashdan & Kane, 2011), as well as the ability to live a life that is consistent with one's core values (Hayes et al., 1999; Wilson & Murrell, 2004). Avoidance coping and denial are in contrast to meaning-making processes, such as deliberate rumination, and involve thoughtful reflection as well as confronting painful and unpleasant emotions, thoughts and sensations that often accompany stressful and traumatic life events.

To reiterate, PTG proposes that acceptance is a precursor to positive psychological change and growth-ful development (Tedeschi & Calhoun, 2004; Calhoun, Cann & Tedeschi, 2010). Present study findings indicate that there were varying levels of acceptance amongst participants, as evidenced in sub-theme 1e: *"Just got to accept it," greater acceptance to the ambiguous nature of PD and life in general.* A prominent topic was acceptance (or lacking) of the caregiver role. Many loved ones (with the exclusion of bereaved caregivers and longer-term caregivers) were grappling with the transition and changes in relationships from a familial to a caregiving relationship, as evidenced in difficulties coming to terms with

assuming the role of the primary caregiver. Caregiver Identity Theory (Montgomery & Kosloski, 2009) could explain this finding by the loved going through a transition from loved one to caregiver. Montgomery and Kosloski (2009) state that caregiving in general is characterised by periods of identity stability and change, which reflect assimilation and accommodation. During this transition, loved ones are required not only to change their behaviour (i.e., performing caregiving activities that have previously not been part of their familial role), but also to change their identity, whereby they come to see themselves as a 'carer' and to integrate the carer role into their previous role identity such as a wife, husband or daughter (Montgomery & Kosloski, 2009).

The revised meaning-making model, *changed identity* (meaning-made) is viewed as an outcome of meaning-making coping processes that include both assimilation and accommodation. In the present study, it appears that during the early stages of the disease, loved ones providing care for persons with PD gradually incorporated a few caregiving activities into their existing views of the spousal or familial relationship, with minimal distress. During these early stages assimilation is often employed, which involves stretching the existing identity to incorporate tasks that may not be fully consistent with the internalised standards and expectations for behaviour that exist for one's identity, as well as standards and expectations for the pre-existing relationship (Montgomery & Kosloski, 2009). In contrast, *accommodation* refers to a fundamental and noticeable shift in the dyadic role relationship, and ultimately in one's role identity. For example, when a loved one comes to realise their person with PD is no longer capable of independently maintaining their own personal hygiene, and thus, is forced to accept the role of the caregiver by assuming responsibility for maintaining the PD sufferer's personal hygiene.

According to the revised meaning-making model, *assimilation* and *accommodation* (see Figure 2) are employed to reduce the discrepancies between appraised situational

meaning and global meaning as a result of the stressful situation. These meaning-making processes are activated because of the motivation to reduce distress by restoring congruence between identity and behaviour, such as caregiving activities and tasks. In turn, this results in a changed identity such as a loved one perceiving his or herself as the primary carer for the affected loved one, and ultimately making a successful adjustment to the PD caregiving situation or caregiving role.

In the present study it was observed that loved ones further along the trajectory, who had been providing care for persons with PD in more advanced stages of the disease, had, in most instances, accepted the caregiving role and change in identity. Seemingly, older caregivers more readily assumed the caregiver role, as evidenced in their self-report at the interview when they described themselves as carers. This was in contrast to younger/middle-aged participants, and loved ones who were not as far along the disease trajectory, who stated that they did not consider themselves as carers. These loved ones acknowledged that whilst they may be required to assume more caregiving activities in the future, primary caregiving was not their present day experience. These loved ones were coping by not thinking about the time when their persons with PD would become dependent upon them.

The loved ones not expecting to care for a partner in mid-life might explain the difficulties in accepting the caregiver role. According to Eriksson and Svedlund (2006), caregiving for a partner in mid-life has been conceptualised as an “off-time” event because it is often viewed as non-normative or unexpected and therefore unrewarding. In contrast, caregiving for a partner in later life is conceptualised as an “on-time” event because it is normative and expected (Carter et al., 2010; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003). Consequently, the carer role can be harder to accept for younger PD caregivers. Nevertheless, Park (2010) states that how individuals achieve a sense of acceptance or coming to terms with a stress or traumatic event remains a relatively unexplored

phenomenon. Thus, further research investigating acceptance in the context of PD caregiving is warranted.

7.3 Summary

The present findings indicated that the experience of living with, and caring for, persons with PD is not limited to stress, burden and even trauma, but included resilience, positive psychological change and growth-ful development, and can be explained by the theoretical model of AAD, PTG and the meaning-making model. Findings show that the PD caregiving situation can expose the loved one providing care to a host of demands and existential issues. Yet, these very same caregiving demands also provide an opportunity for positive changes and growth-ful development. These findings are consistent with previous caregiving studies that have shown caregiving provides an opportunity for growth-ful development. The experience of having a loved one provide care presented an opportunity for positively changing their outlook on life, as well as an opportunity for personal growth such as developing interpersonal skills like patience, adaptability and flexibility, and becoming more respectful of personal boundaries. Moreover, this helped to strengthen their relationships with their PWP and family members. The present study findings support the PTG theory that proposes “deliberate rumination, acceptance and social support are not only predictors” of positive psychological change and growth-ful development, but are “best to explain growth” (Tedeschi & Calhoun, 2004, p.99).

The study findings show that positive psychological changes and growth-ful developments are not a cultural phenomenon (e.g., not limited to Singaporean PD caregivers), and are not limited to adult-children providing supplementary for parents with PD. Findings show that the PD caregiving situation provided loved ones with an opportunity to meet existential needs in accordance with Cohen’s (2002) developmental theory for adults

in later life, such as a sense of urgency to find greater meaning in life, contribute positively to others and resolving unfinished business.

However, not all loved ones reported self-perceived positive psychological change and growth-ful development. According to the meaning-making model these individuals may have been too overwhelmed by the demands of the PD caregiving situation to report positive experience or growth-ful development. On the other hand, loved ones with PD sufferers in the early-to-mid stages of PD, who were not required to provide any, or at most minimal assistance, may not have felt challenged by the PD caregiving situation. Consequently, the activation of meaning-making coping processes that result in positive outcomes were not required, as explained by both the revised meaning-making model and post-traumatic growth theory.

Some loved ones did not report any positive or negative changes associated with caregiving. According to AAD theory (Papadopoulos, 2007) this reflects a neutral (or resilient) response to the PD caregiving situation. Whereby the loved ones could be successfully adjusting to and coping with the PD experience. These loved ones seemed to consider the possessed adequate resources (e.g., social support, personal skills and self-efficacy) to deal with the demands of the PD caregiving situation.

Furthermore, according to the most recent theoretical model of PTG (Calhoun, Cann, & Tedeschi 2010) these loved ones did not report positive psychological changes and growth-ful development because they may have easily fit the PD diagnosis and caregiving experience into their assumptive beliefs, without disruption to their personal goals, narratives or worldview. Thus these individuals may not have engaged in meaning-making processes leading to PTG, yet still reported a sense of well-being and life-satisfaction. This was reflected in loved one's accounts in *sub-theme 5b: PD doesn't interfere with our lives or relationship*.

Chapter Eight: Clinical and Practical Implications, Strengths, Limitations and Future Research Directions

The purpose of this chapter is to discuss the clinical and practical implications, methodological strengths and limitations of the present study, and directions of future research. This chapter will first present the clinical and practical implications, and recommendations of the study's findings. Next, this chapter will outline the methodological strengths, which include participant benefits, and trustworthiness of the study. This chapter will then outline the methodological limitations, and recommendations will be made for future research to overcome these limitations wherever possible.

8.1 Clinical and Practical Implications

8.1.1 Create an environment conducive to growth-ful development. The sub-theme 5b: *PD doesn't interfere with our lives or relationship* clearly demonstrated that during the early-to-mid stages of PD, symptoms are managed by medication, and persons with PD are largely able to carry on as normal. The positive effects of medication, compounded by insufficient knowledge about the debilitating nature of PD, have potential to create a false sense of normalcy. This implies a contextual environment conducive to minimal change (positive or negative), and possibly low levels of stress, compared to later stages of PD. As previously mentioned, influential growth theories/models (e.g., Bonanno, 2004; Calhoun, Cann & Tedeschi, 2010; Park, 2010) postulate that an environment of moderate amount of stress explains positive psychological change and growth-ful development as opposed to extremely high or low stress. Moreover, the sub-theme 4a: *Meanings-made about the PD at the time of diagnosis* implies that the meanings loved ones make of having a family member diagnosed with PD is relevant in terms of whether they eventually make positive changes (i.e., ways of thinking, being and making the most of new opportunities). It is therefore recommended that at the time of diagnosis, the loved ones are fully informed about the

debilitating nature of PD and possible long-term negative impacts of PD on their lives, such as diminished quality of life and the inability to pursue life goals. This knowledge may create an environment of moderate stress (as opposed to low stress) conducive to positive change and growthful development by activating meaning-making processes necessary for positive change.

However, by fully informing the loved ones about the debilitating nature of PD, there is the risk that loved ones, especially those lacking in support may become overwhelmed (sub-theme 5a: *No positive changes, only negative*). Growth theorists (e.g., Bonanno, 2004; Park, 2010; Tedeschi & Calhoun, 2004) postulate that contemplating trauma-related thoughts in a supportive and comforting social environment helps alleviate the intensity of the distress. This can further aid cognitive processing process without loved ones becoming overwhelmed, and in turn hampering a growth-experience. Therefore, it is recommended that the loved ones are provided with the opportunity to attend one-on-one sessions with a mental health professional at the time of diagnosis to cognitively process the diagnosis in a supportive environment.

8.1.2 Referral to psychological services. Loved ones who report a lack of positive psychological change and growthful development since their loved ones was diagnosed with PD may be referred for psychological services. The mental health professionals should be well-versed in the innumerable of ways people are confronted by life-limiting and life-threatening diseases. In addition, the mental health professionals should be competent in interventions and strategies to assist people through such challenges. One-on-one sessions have the potential to provide an emotionally supportive environment for loved ones to contemplate imminent changes and losses associated with PD, to process their emotional response to the diagnosis more deeply, to facilitate acceptance and adjustment to PD, to

revise comprehension systems (e.g., beliefs, schemas, and meaning), and to contemplate life goals and expectations in light of the PD diagnosis.

These psychological sessions may be of particular benefit to those loved ones who do not feel emotionally supported by their family or person with PD. The sub-theme 5b: *Person with PD experience* indicated that the loved one's experience is influenced (either positively or negatively) by their person with PD. Some loved ones described the diagnosis experience as stressful and conceptualised this, as their persons with PD's denial. These loved ones stated their person with PD did not accept the disease, and did not want to talk about the PD diagnosis or imminent changes; rather their person with PD wished to carry on as normal. They reported that it was difficult to discuss their feelings with their family, friends and their affected family member because of their persons with PD's denial and lack of acceptance of the disease. Ultimately, the loved ones felt unsupported.

8.1.3 Possible psychological interventions. The present findings identified that deliberate rumination, acceptance, flexibility, and adaptability, were relevant in self-perceived positive psychological changes and growthful development. These areas are possible targets for psychological intervention. This in turn, may promote overall well-being, maintain quality of life, buffer against caregiver burden and depression, improve the quality of care to the persons with PD and reduce the likelihood of premature nursing home placement, and consequently health-care costs.

It is recommended that psychology professionals working with the loved ones providing care for persons with PD should design psychological interventions from a strength-based perspective. Professionals can be guided by recent strength-based treatment protocols designed to facilitate post-traumatic growth in breast cancer patients (see Ramos, Leal, & Tedeschi, 2016). Psychology professionals are encouraged to adopt an eclectic approach, tailor made to client(s) needs utilising principles of acceptance and commitment

therapy (ACT), positive psychology, humanistic-existential psychotherapy, and narrative theory. Psychological interventions should be designed to enhance cognitive skills in the following areas: identification of personal strengths, facilitating deliberate rumination and life reflection, savouring the awakening experience, values clarification, fostering mind-ful acceptance coping, and enhancing psychological flexibility to encourage positive psychological changes and growth-ful developments. These adaptive cognitive skills will now be expanded upon.

8.1.3.1 Identification and mobilisation of personal strengths. The gain-related findings of this study, and those of other strength-based studies (e.g., Peacock et al., 2010) provide a rationale to recognise positive changes and growth-ful development in PD caregivers. That is, adopt a strength-based approach in the development of psychological interventions, rather than an exclusively pathology-focused (or deficits-based) approach focussed on symptom reduction. Whilst it is acknowledged the pressure to think positively is not helpful (Held, 2002), those who are unable to reported any positive psychological changes or growth-ful development since having a loved one diagnosed with PD should be helped to identify the positive aspects of PD caregiving and areas of growth-ful development, such as personal strengths. Through adopting principles of positive psychology (see Ciarrochi, Kashdan, & Harris, 2013; Ramos, Leal, & Tedeschi, 2016; Seligman, 2011) loved ones providing care should be assisted in the mobilisation of these personal strengths for positive adjustment to the PD caregiving role.

It is recommended for diagnosing and treating medical practitioners to provide a more complete view of PD caregiving, such as detailing of the negative impacts of the disease, and also emphasising the possible positive opportunities that the PD experience presents. Psychology professionals working with this population need to respect the nature of PD whilst simultaneously adopting a strengths-based perspective, and introduce (and reflect)

observations in relation to positive aspects associated with caregiving (e.g., demonstration of courage, resourcefulness and personal strength), and encourage opportunities for growthful developments, such as personal and relationship growth. It is recommended that throughout the treatment process questions associated with the intervention of reducing feelings of strain, should be followed-up with questions related to any feelings of gain developed within the caregiver. This supports the shift away from the deficit-based focus.

8.1.3.2 Facilitation of deliberate rumination. Based on the sub-theme 1a: *Making the most of life though re-evaluation and re-prioritisation* it is recommended that clinicians working with this population encourage the loved ones to revise goals, life plans, and attitudes to make the most of life whilst the persons with PD are still physically and cognitively able to enjoy and engage in pleasurable and meaningful pursuits. Especially those loved ones who appear to be succumbing to a false sense of normalcy (sub-theme 5b: *PD doesn't interfere with our lives or relationship*) and/or those loved ones who are unable to acknowledge any positive changes in thinking or being since their person with PD was diagnosed with the disease (theme 5: *Lacking in positive changes and growthful development*).

Psychological interventions should be designed to move loved ones from an everyday mode of existence to an ontological mode of existence (Yalom, 2008). This may be of particular benefit to those loved ones experiencing difficulty accepting the changes brought on by PD and the caregiving role, and/or those who are relying on avoidance coping strategies (i.e., actively avoiding contemplating the imminent changes and negative impacts on the disease on their future) (Sub-theme 1e: *"Just got to accept it," greater acceptance for the ambiguous nature of PD and life in general* and Master Theme 5: *Lacking in positive psychological changes and growthful development*).

In a supportive therapeutic encounter, an existential- humanistic approach could be applied (Yalom, 2008) allowing loved ones to ponder existential questions and to re-evaluate their lives in light of the PD diagnosis. The existential-humanistic approach could be aimed at life-reflection and contemplating imminent changes imposed by PD, sense-making and make-sense and forging meaning about the PD diagnosis, and facilitation and savouring the awakening experience in the aftermath of the PD diagnosis.

It has been found that as time passes following the threat of mortality, people typically regress to their accustomed, habitual ways of thinking and being (Aldwin, 2011). Therefore, loved ones should be encouraged to adopt a mindful approach to living (see Garland & Fredrickson, 2013; Garland, Gaylord, & Park, 2009) in order to savour the awakening experience post PD diagnosis, to take full advantage of the time they have left with their person with PD, and to live the most meaningful life in the presence of PD and the PD caregiving situation.

In this regard, psychological intervention stands to have benefit not just around the time of the PD diagnosis, but at critical junctures during the PD caregiving journey. For example, this type of support could be provided around the time when medication becomes ineffective and no longer masks the debilitating effects of PD, or around the time of pre-and post-surgery, nursing home placement, and bereavement. During these critical junctures, it may be anticipated that PD caregivers may be confronted with mortality, and such support could provide an opportunity for an awakening experience for positive psychological changes and growth-ful development. A referral to a mental health professional may support the experience when a loved one is struggling to make-sense and finding meaning in their personal situation, and /or, experiencing grief and loss; and/or grappling with existential conflicts such as mortality, meaningfulness versus meaninglessness, and freedom versus responsibility. In addition to the existential-humanistic approach, a narrative approach and

therapeutic diaries may also be considered (Hallam & Morris, 2013; Neimeyer, Prigerson, & Davies, 2002; Vrielynck, Philippot, & Rimé, 2010), or even an integrative approach to help the loved ones make sense, find meaning, and explore painful experiences associated with PD caregiving.

8.1.3.3 Values clarification. Findings show that the PD diagnosis provided impetus for loved ones of those diagnosed with PD to clarify what was important and of value to them (sub-theme 1a: *“Making the most of life” through re-evaluation and re-prioritisation*), and as a result revise life goals, beliefs and sense of meaning (e.g., sub-theme 1a: *Making the most of life through re-evaluation and re-prioritisation*, sub-theme 1b: *Finding meaning in caregiving through benefit-finding and positive appraisal*, and sub-theme 1c: *Touched by PD, the desire to contribute positively to others*). Revisions to global meaning, resulted in engagement in meaningful activities in accordance with their personal values (e.g., spending more quality time with their person with PD, which strengthened their relationship with that person (sub-theme 3a: *Closer to person with PD*). Loved ones came to recognise that the experience of having a loved one diagnosed with PD presented new opportunities to find meaning in life, either through the caregiving situation (sub-theme 2b: *“Finding meaning in caregiving” through benefit-finding and positive appraisal*) and/or helping others who are also affected by PD (sub-theme 2c: *“Touched by PD,” the desire to contribute positively to others affected by PD* and sub-theme 4e: *Support groups*), which provided them with a restored sense of value, meaningfulness, and importance.

However, findings also demonstrated that some were unable to ascribe any positive meaning to their caregiving situation. Rather, they could only ascribe negative meaning and describe the caregiving situation as a sense of obligation. Some stated they had not fully accepted they would have to assume the caregiving role.

Loved ones who only report strains, loss, and lack of positive meaning associated with the PD caregiving experience could be assisted to discern and clarify their personal values, though interventions such as *values clarification exercises* (Harris, 2009). These may help individuals to revise and clarify a newly emerging comprehension system (or global meaning, such as revision of beliefs, goals, sense of meaning, and values) in the wake of PD. The objective of any values clarification exercise is to bring a sense of choice, freedom, and meaning to the caregiving role (Márquez-González, Romero-Moreno, & Losada, 2010). Loved ones providing care may come to realise that even though they did not choose the PD diagnosis or the caregiving situation, they can choose their attitude and to behave or act in accordance with their personal values when confronted with the implications of the disease. This in turn, can create meaning for caregiving tasks and transform the caregiving experiences from a sense of obligatory routine into a sense of choice. for those who ascribed the caregiving situation as burdensome, negative and obligatory (sub-theme 5a: *No positives only negatives*).

Given the progressive nature of PD, loved ones providing care are required to remain committed and dedicated to the caregiving role, over an extended period of time, typically until the death of his or her person with PD. It is considered essential to help loved ones find meaning and a sense of purpose in the PD caregiving situation. There is substantial literature on meaning and purpose in life that seems to be linked to values (Ciarrochi et al., 2013; Compton & Hoffman, 2013; Steger, Kashdan, Sullivan, & Lorentz, 2008). A purpose or sense of meaning provides a foundation that allows the loved ones to be more resilient to demands, stress, and burden associated with caregiving (Carlisle, 2000; Farran et al., 1999; Konstam et al., 2003), and to persist with valued action when confronted with long-lasting and difficult challenges (Steger, Sheline, Merriman, & Kashdan, 2013), such as the challenges and adversities the loved ones are exposed to during the caregiving situation. For

example, when there is a discrepancy between valued preferences (e.g., being compassionate towards others) and actual behaviours (e.g., behaving selfishly without regard for another's feelings), this could potentially be a pivotal point for intervention (Ciarrochi et al., 2013; Harris, 2009; Losada et al., 2012). If successful such intervention has the potential to result in self-perceived positive psychological changes and growth-ful development (e.g., becoming more compassionate and aware of others' needs), and enhance relationship with the person with PD.

8.1.3.4 Foster mindful-acceptance coping. Present study findings indicated that the loved ones providing care are faced with multiple losses, and a feeling that they have lost control with regards to the disease trajectory because of PD's constantly changing and unpredictable nature (e.g., sub-theme 1e: *"Just got to accept it," greater acceptance of the ambiguous nature of PD and life in general* and Master Theme 5: *Lacking in positive psychological changes and growth-ful developments*). Findings indicate that loved ones who reported positive psychological changes had accepted the PD diagnosis, and were more accepting of the unchangeable aspects of the disease and the losses that can accompany PD. However there was evidence that many loved were grappling with the losses and had not fully accepted PD (sub-theme 1e: *"Just got to accept it," greater acceptance of the ambiguous nature of PD and life in general* and Master Theme 5: *Lacking in positive psychological changes and growth-ful development*). Thus, it is recommended that psychological interventions for this population are designed to assist in fostering an attitude of acceptance to help positively adjustment to the caregiving situation.

Acceptance and Commitment Therapy is derived from cognitive-behavioural therapy (CBT) and has proven especially useful for presentations or disorders with unchangeable aspects (Hayes, Strosahl, & Wilson, 1999), such as a parent's emotional distress over their child's developmental disorder (Blackledge & Hayes, 2006), chronic pain (McCracken &

Eccleston, 2005) and family members' emotional distress over persons with dementia (Losada, Márquez-González, & Romero-Moreno, 2011; Losada, Márquez-González, Romero-Moreno, & Lopez, 2014; Losada et al., 2012; Márquez-González et al., 2010). ACT teaches skills to help individuals accept what is outside of their personal control, and commit to valued action to improve and enrich quality of life (Ciarrochi et al., 2013). ACT assumes that even in the midst of tremendous pain and suffering, there is an opportunity to find meaning, purpose, and vitality (Harris, 2009, 2012; Hayes et al., 1999). Hence, ACT may prove to be both an effective and efficacious form of therapy for the loved ones providing care for persons with PD, because like dementia caregivers, loved ones are required to not only face but also accept an uncontrollable and incurable disease that causes unavoidable suffering and unchangeable loss (Losada et al., 2012).

It is therefore recommended that the loved ones providing care may benefit from interventions aimed at fostering *mindful acceptance coping* (see Garland & Fredrickson, 2013; Garland et al., 2009), with the view to elevate positive psychological changes and growth-ful-development. Mindfulness broadly defined, means conscious awareness with an open, receptive and accepting attitude of what is happening in the present moment (Williams, 2008). A state of mindfulness is characterised by turning one's attention towards one's experience rather than away from it, whether it be a moment of joy or pain (Ciarrochi et al., 2013; Garland & Fredrickson, 2013). It has been found that in a mindful state, individuals are better able to focus attention and to explore one's environment with an appreciation of novelty, challenge and uncertainty, rather than in a non-mindful state (Silvia and Kashdan, 2009). This has implications for the present study because, similar to previous studies (Dyck, 2009; Habermann, 2000; Wressle et al., 2007), loved ones providing care for persons with PD expressed difficulties in dealing with the uncertain and unpredictable nature of PD. Therefore, teaching mindfulness skills may help loved ones providing care to deal with and

accept the uncertainty that accompanies the PD caregiving situation and the unpredictable and constantly changing nature of PD.

8.1.3.5 Facilitation of positive reappraisal. Loved ones who are struggling to find benefit or meaning in the caregiving situation may be encouraged to attend training in positive reappraisal. Teaching mindfulness to loved ones providing care may also facilitate healthy cognitive skills such as positive reappraisal (see Garland & Fredrickson, 2013; Garland et al., 2009). Garland and Fredrickson (2013) maintain that the state of mindfulness can moderate the impact of potentially distressing psychological content through cognitive processes referred to as *de-centering* (Segal, Williams, & Teasdale, 2013) and *re-perceiving* (Shapiro, Carlson, Astin, & Freedman, 2006), which involve stepping back from thoughts, emotions and sensations. Garland and Fredrickson propose that for an individual to positively reappraise an event or situation as positive, he or she must first suspend the initial stress appraisal and disengage cognitive resources from it, such as letting go or de-centering, from the stress appraisal and attain the state of mindfulness. As a result, individuals can access new data with which to appraise their circumstances and reframe them as meaningful and beneficial (Fredrickson et al., 2003), which is self-perceived positive psychological changes and growth-ful development.

However, this proposal has limited empirical evidence, but nevertheless, there is currently some randomised control research underway to investigate how best to facilitate positive reappraisal in a clinical setting (Garland & Fredrickson, 2013). This research could be extended to the loved ones providing care for persons with PD. Notably, there are promising findings of mindfulness training effectiveness in dementia caregivers (Hoppes, Bryce, Hellman, & Finlay, 2012).

8.1.3.6 Enhancement of psychological flexibility. It was evident in sub-theme 2c: *Becoming more adaptable* that PD caregiving requires adaptability and flexibility. It is

recommended that loved ones may benefit from psychological interventions aimed at improving flexibility and adaptability to assist with PD management and promote growthful-development in the caregiving situation. Kashdan & Rottenberg (2010, p. 865) state that:

“Psychological flexibility spans a wide range of human abilities to: recognise and adapt to various situational demands; shift mindsets or behavioural repertoires when these strategies compromise personal or social functioning; maintain balance among important life domains; and be aware, open, and committed to behaviours that are congruent with deeply held values”.

The primary goal of ACT is to increase psychological flexibility because it works on the premise that it is the foundation of living a rich, full and meaningful life (Ciarrochi et al., 2013). Psychological flexibility is negatively associated with depression, anxiety and psychopathology, and positively associated with quality of life (Fledderus, Bohlmeijer, Smit, & Westerhof, 2010; Kashdan & Rottenberg, 2010; McCracken & Zhao-O'Brien, 2010).

8.1.3.7 Respecting boundaries. By navigating their way through problems and difficulties incurred during the caregiving situation, many loved ones perceived they had become more patient, sensitive and respectful of the person with PD's existential needs (e.g., autonomy and independence), and in turn, perceived that they were better at respecting their person with PD personal boundaries (sub-theme 2a: *Improved interpersonal skills* pertaining to *interpersonal sensitivity and respect*). This implies that loved ones who identified that they struggled with a sense of impatience, and reported conflict and tension as a result of the person with PD feeling nagged, controlled or disempowered by the loved one could be provided with psychological interventions aimed at sustaining and maintaining personal boundaries. Such interventions have potential to benefit not only the loved ones providing care in the caregiving situation, but also the persons with PD in terms of their psychological well-being. Deci and Ryan (2000) maintain that psychological health involves people

needing to feel connected to others, to feel a sense of mastery and competence, and/or believing their behaviours, goals, and values are freely chosen (Kashdan & Rottenberg, 2000, p. 866).

8.1.4 Create opportunities for growth-orientated individuals in the PD community. The sub-theme 1c: *“Touched by PD,” the desire to contribute positively to others affected by PD*’ helped loved ones to cope and find meaning in their experience of having a loved one with PD. It is recommended that not only is this to be encouraged, but opportunities should be created for growth-orientated PD caregivers to volunteer and share their growth experiences with others in the PD community. Loved ones who report and emulate positive transformation and growth-ful development as a result of the PD caregiving situation should be invited to share their growth-narratives with others (i.e., presenting at PD support groups). Growth narratives may include narratives of personal mastery, such as how they perceived they had derived interpersonal skills since providing care. These growth-orientated loved ones have a potential to serve and act as positive role models. PTG proposes that positive psychological change and growth-ful development are more likely when individuals are exposed to others with a similar fate and then positively adjust and grow from the experiences (Tedeschi & Calhoun, 2004; Weiss, 2004). Moreover, the spreading of growth narratives may positively transcend others in the PD community through vicarious positive transformation and growth-ful development (Tedeschi & Calhoun, 2004), and consequently challenge them to initiate beneficial changes (Bloom, 1998; Karakasian, 1998; Tedeschi, 1999). Furthermore, these growth-orientated loved ones could demonstrate a more balanced, holistic view of PD caregiving (both positive and negative).

8.1.4 Becoming an expert companion for others. Growth-motivated loved ones providing care for persons with PD, who are experienced informal caregivers with a drive for personal growth, as well as helping others, may be trained as an *expert companion* (Calhoun,

Tedeschi, Cann, & Hanks, 2010). Calhoun et al., (2010) propose that an expert companion may produce benefits by promoting ruminative processing, as well as providing comfort and reassurance to others who share their fate. This surpasses the support often given by well-meaning friends and family who typically provide comfort and reassurance with platitudes, (Hallam et al., 2013). Rather, they can assume the role of a non-judgmental listener, as well as providing advice and guidance if required given their own personal understanding of the PD caregiving situation. Such a companion should have the courage to hear unpleasant and painful stories as well as the appreciation for the paradox, which in the vulnerability of loss and grief, can emerge strength and growth-ful development.

This kind of support may be an effective substitute for partner support, particularly for loved one providing care for family members who are either emotionally unsupportive, or whose emotional support has declined because the disease negatively affects their emotional functioning (Shirai et al., 2009). Furthermore, these expert companions could co-facilitate psycho-educational and therapeutic groups with a qualified mental health professional (e.g., psychologist) within the PD community.

8.1.5 Encourage support group attendance. The present study revealed many benefits for support group attendance. To reiterate, support groups appeared to be fertile ground for positive psychological changes and growth-ful development. Similar to what Tan et al. (2012) suggested, loved ones should be encouraged, rather than discouraged, to attend PD support groups. Emotional expression, as well as sharing knowledge and experiences should be encouraged. Support groups may also provide a good opportunity to foster and maintain healthy social networks.

8.1.6 Encourage engagement in physical activity and yoga. It is also recommended that PD caregivers are also encouraged to engage in physical activity, possibly with their person with PD because exercise has been found to benefit persons with PD in terms of

improved cognitive and physical abilities as well as psychological well-being (Ahlskog, 2011; Li et al., 2014; Tanaka et al., 2009). A growing body of research confirming the crucial role that a physically active lifestyle plays in maintaining and improving physical health and mental health (Bryan & Katzmarzyk, 2011; Fuchs, Goehner, & Seelig, 2011; Windle, Hughes, Linck, Russell, & Woods, 2010).

Exercise (Ahlskog, 2011) and yoga (de Manincor et al., 2016) have been found to be effective treatments for mild and moderate depression, across age spans (Wipfli, Landers, Nagoshi, & Ringenbach, 2011). Exercise offers an opportunity to engage in a non-stigmatising activity that may hold appeal for difficult-to-reach client populations (Mead, et al., 2009) such as loved ones providing care for persons with Parkinson's disease at home. Thus, caregivers should be encouraged to engage in physical activity and /or yoga, in order to buffer against the negative effects of PD caregiving such as depression and burden.

8.2 Methodological Strengths

The present study addressed the gap in the PD caregiving literature by redressing the imbalance of the relatively exclusive focus on the negative aspects over the positive aspects of PD caregiving. The present study used a qualitative method of enquiry, and adopted an IPA approach to explore the PD caregiving experience, from a strength-based perspective. This mode of enquiry and methodological approach had the potential to benefit participants, and possibly their persons with PD.

First, the focus of the present study provided participants with the opportunity to reflect on the positive aspects of caregiving. Previous research has found that informal family caregivers resented being asked about the burden and strain associated with caregiving. Rather, they wanted an opportunity to discuss the positive side of caregiving (e.g., Addington-Hall & Ramirez, 2006; Habermann, 2000; Kramer, 1997). Hence, this study addressed this unmet need in some ways.

Second, the IPA approach required the researcher to adopt a phenomenological attitude; that is an attitude of openness, plus attentiveness to, and curiosity for the participant's experience (Willig, 2013). If successful in sustaining this phenomenological attitude, the researcher creates an environment where participants are likely to feel they have been heard, understood, and validated, during the process of sharing their stories about the trials, tribulations, joys, gains and satisfactions associated with their PD experience. This may be a potential benefit for those participants involved in this study, considering in the past when PD caregivers had expressed feeling that they did not have a voice, and were on the peripheral of PD treatment and research endeavours (McLaughlin et al., 2011). Moreover, the phenomenological approach is more likely to garner information about the true life world needs for the loved ones providing care for persons with PD, rather than researchers interpreting those caregiving needs based on deductive findings.

Third, the qualitative method of inquiry allowed the researcher to facilitate rapport with participants, and to demonstrate empathetic understanding and positive regard. In addition, this interview method allowed for greater flexibility, and presents an opportunity for the interviewee to lead the interview and discuss interests and concerns that are most relevant and meaningful to their lived experience (Smith & Eatough, 2012; Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008). This method had potential to empower those that participated in this study. However, the drawback of the IPA approach is that it requires conviction of the researcher, to let go of control of the interview and to trust that whatever should emerge as a result of the interview, will emerge (Smith & Eatough, 2012; Smith & Osborn, 2008).

It is recognised in the positive psychology literature that by assisting people in identifying and clarifying personal strengths, values, and virtues; serves to cultivate or enhance positive emotions, experiences and relationships, and ultimately promote growth-ful

development (Ciarrochi et al., 2013; Csikszentmihalyi, 2014; Seligman, 2011). Therefore, it may be that the research project, presented an opportunity to recognise areas of personal strength and growth-ful development that may not have been realised prior to the research interview. Further, by identifying the positive aspects of PD caregiving and personal strength it has potential to result in self-enhancement and improved quality of care provision for persons with PD. However, it is recognised that this is only a suggestion and requires further investigation.

Fourth, the researcher considered the focus group addition as a methodological strength. Even though this mode of data collection differed from the interview, the broad analytic strategy, types of responses from participants, and the emergent themes did not. This finding is consistent with the works of De Visser & Smith (2007) who also used interviews and focus groups in their IPA study. The use of the supplementary focus group served to validate the emergent themes identified in data phase one (interviews). In the present study, no participant at the group appeared compromised by the presence of other participants, rather, each actively engaged and shared personal and sensitive information with others and the researcher. In numerous instances, other participants helped validate personal disclosures. Collectively the group generated a stimulating discussion that allowed the researcher to arrive at a clearer and richer understanding of the lived experience of providing care for PWP, beyond the information that was collected at the interviews, as evidenced in the transcripts. Most importantly, data garnered at the group revealed unique and novel findings.

Despite concerns about the level of compatibility for focus groups as a data collection method for IPA studies (Webb & Kevern, 2001), the researcher agrees with Bradbury-Jones et al. (2009), Dunne and Quayle (2001), and Flowers et al. (2001) that focus groups are an

appropriate method for IPA. It is concluded that focus group discussions should be both encouraged and recommended for further IPA research studies.

Despite these methodological strengths, and possible benefits for the research participants, the present study was not without limitations. There were several limitations in terms of the chosen methodology, design, sample, and data collection methods, which further research could address in some instances.

8.3 Methodological Limitations

Interpretative Phenomenological Analysis is not without its drawbacks (Smith & Eatough, 2012; Willig, 2013). First and foremost, IPA is consistently criticised for its susceptibility to researcher biases due to the subjective nature of the researcher's role (Holliday, 2007). It is recognised that this project has been influenced by the researcher's personal and professional experience. It is acknowledged that the possibility of another researcher, answering the same research questions within the same methodological framework, as well as following identical guides and processes employed in the present study, might have foregrounded different aspects of the data. This could result in different themes, sub-themes and ultimately different implications and recommendations, compared to this study. However, IPA is distinct from quantitative methodologies and does not strive to remove the influence that the researcher has on the research data and findings. Rather, as previously mentioned in Chapter Three, IPA acknowledges the active role of the researcher, an instrument in the research, and utilises personal psychological knowledge as well as psychological theory in an attempt to understand the true essence of the phenomenon under-investigation (Smith & Eatough, 2012).

In accordance with guidelines for conducting IPA studies, several verification strategies were employed to minimise the possibility of the data's integrity being unnecessarily compromised by researcher's biases, and to maximise the phenomenological

attitude during the course of this project. That is, the researcher “becomes fully aware of what is actually before them” (Willig, 2001, p. 52), such as the research participant or the interview transcript, rather than being caught up in their own taken-for-granted assumptions and preconceptions. Although measures were taken to minimise researcher bias, ‘as with all research, there is really no way to confirm that biases did not inappropriately inform the data collection and analysis processes’ (Blanchard et al., 2009, p. 75).

The second methodological limitation was that the cross-sectional design employed meant that participants’ PD caregiving experience was only examined at one particular point in time along their PD caregiving journey. In its orientation toward a particular timeframe, this cross-sectional design does not adequately capture information concerning antecedents and outcomes of a particular experience. Nonetheless, the goal of this study was not to confirm what personal and contextual factors predict positive psychological changes and growth-ful developments during the PD caregiving situation. This study aimed to lay the foundations for future research to build upon, in terms of contextual factors of growth-ful development in loved ones providing care for persons with PD. Only prospective, longitudinal research designs can demonstrate how positive psychological changes and growth-ful development evolve over time. Hence a possible progression for further research could adopt a mixed-method approach to expand upon the knowledge garnered at the present study, as well as to address limitations of its cross-sectional design. For example, further research may adopt the Bacon et al. (2009) mixed-method approach and conduct a longitudinal case-series study. Bacon et al. used a combination of qualitative methods including semi-structured interviews, diary log entries; and quantitative methods to measure self-perceived positive psychological changes and growth-ful development in stroke caregivers. Results demonstrated that self-reported positive experiences and growth-ful development varied markedly on a day-to-day basis. This variation illustrates the importance

of a longitudinal methodology to best capture the PD caregiving situation. This type of research could build upon present findings and better understand not only the psychological processes necessary for growth-ful development, but also how positive experiences fluctuate and change during the caregiving situation.

A third limitation pertained to the sample. This study comprised of a diverse sample with differing demographic and contextual characteristics. This may be considered a strength because similar experiences were found across this diverse sample. Furthermore, the variability amongst participants in terms of the overall caregiving duration in this study also helped understand long-term consequences of PD caregiving. Findings revealed that the PD sufferer's stage of the disease appeared to influence the loved ones' reports of positive psychological changes and growth-ful development. Thus, a direction of future research may be to conduct a cross-sectional study comparing loved ones providing care for persons with PD in various stages of PD and track similarities and differences in reports of positive psychological changes and growth-ful development at the different stages of PD (e.g., early, mid and late stage).

Adding to this issue with diversity, the original inclusion criteria stipulated that participants must be the primary caregivers for a spouse, diagnosed with PD. However, there were initial problems gaining enough participants (spouses) for the study and as a result the inclusion criteria were broadened. The scope was broadened to include not only spouses, but also other family members (such as adult children) who were the primary caregiver for persons with PD, as well as widowed PD caregivers.

According to Smith and Eatough (2012) it is not unusual to adapt the inclusion criteria when there is inadequate number of participants. However, a limitation is that widowed caregivers no longer fulfil the role of a primary carer. Thus the inclusion of bereaved caregivers may have skewed findings, because positive changes and growth-ful

development may have been activated by the death of their loved ones instead of the PD caregiving experience. In the present study, bereaved caregivers described more examples of positive psychological change and growth-ful development compared to any other participant. Therefore, this factor could have inflated positive psychological changes and growth-ful development in the present study. As such, future research endeavours could compare similarities and differences between primary PD caregivers and bereaved PD caregivers.

Another limitation related to the sample was that the present study attempted to address shortfalls in previous studies (e.g., Blanchard et al., 2009; Hallam & Morris, 2013; Sanders, 2005) by recruiting participants from PD supports groups, and other sources. However, the majority of this study's sample comprised participants who were members of their local PA and/or PD support groups. Indeed, four participants were volunteers at their local PA association, and described being intensively involved in their local PD community. Parveen and Morrison (2012) stated that it is now the norm that caregivers are recruited from support groups. However, Hallam and Morris (2013) and Blanchard et al. (2009) acknowledge that there are problems with participants solely sourced from PD support groups because individuals who attend PD support groups may be qualitatively different than those who do not.

There is evidence that demonstrates caregivers who attend associations and support groups score higher on optimism and extraversion than those who do not (Anderson, 1988; Mo & Coulson, 2013). Optimism and extraversion have been found to elevate positive psychological changes and growth-ful development (Liew et al., 2010; Tedeschi & Calhoun, 2004). Further, Liew et al. (2010) found support group attendance was positively associated with self-perceived positive psychological changes and growth-ful development in dementia caregivers. Blanchard et al. (2009) acknowledge that loved ones (and their persons with PD)

involved in a PD support group implies that these individuals are “connected to external supports and are seeking knowledge willingly.” Therefore, loved ones who “are not involved in a support group may experience the phenomenon quite differently” (p. 76).

Moreover, some participants learned of the present project through their persons with PD, via the PD support group, and were encouraged to partake in this project by that person. Therefore, those who agreed to partake in the study may be different than those who did not (Goldsworthy & Knowles, 2008). These participants’ willingness to engage in the project may reflect more supportive and less conflicted relationship. This may have resulted in a sample comprised of less conflicted and a more socially supportive (and supported) couples or adult child-parent relationships. This in turn may influence present findings because good quality relationship elevates growth-ful development (Weiss, 2004). These factors could have also inflated study findings pertaining to positive psychological changes and growth-ful development. Subsequently, this sample may not be representative of the general PD caregiving population. Notwithstanding, this study was not concerned with generalisability because like all phenomenological research, this study was interested in accurately reflecting a loved one’s experience (Boss & Dahl, 2005).

Nevertheless, a direction for future research may be to focus on those loved ones who are not in a support group. Research with an IPA approach may assist in understanding how these groups are qualitatively different, and how they experience PD caregiving. These groups may require support and psychological intervention.

A fourth possible limitation was that the majority of the interviews were conducted by telephone. This can be advantageous, especially for the loved ones providing care for persons with PD, because telephone interviews permit the participants to remain at home (McCoyd & Kerson, 2006) with their person with PD. On the other hand, telephone interviews also raise some limitations. In this study, telephone interviews posed a dilemma

because at some of the interviews, it was evident that the person with PD was present, which may have limited or influenced the participant's disclosure. It was difficult to make provision for this unknown, as opposed to face-to-face interviews, where persons with PD were advised not to attend. These participants who were interviewed in the presence of their person with PD may have withheld their negative thoughts and feelings about their experience, and may have felt pressure to report positives associated with their PD situation, in an attempt to protect their persons with PD, or risk upsetting their persons with PD unnecessarily. This could have implications on study findings because these participants may have overstated the positive experiences associated with PD caregiving. However, analysis of these participants revealed that their disclosures were overly positive compared to participants whose person with PD was not present.

Nevertheless, at the first and only face-to-face interview, the person with PD was present in the present study. The person with PD's account contributed to understanding the phenomenon under-investigation. Hodgson et al. (2004) also adopted a phenomenological approach, and interviewed both persons with PD and the PD caregiver together. Hodgson et al. argued that this helped to uncover the "rich landscape" of the couple's PD experience in detail, as opposed to limiting disclosure (p. 103). Including persons with PD, and asking them about their loved ones' growthful development since PD caregiving, provides an opportunity to triangulate responses as a tool to validate caregivers' self-perceived psychological changes and growthful development, and also to provide greater thematic depth about the phenomenon.

Another direction for further research may be to investigate positive psychological changes and growthful development in persons with PD. Qualitative and quantitative data collected from both the persons with PD and the loved ones of persons with PD about their self-perceived positive psychological changes and growthful developments could be

compared and contrasted. Findings may confirm or reject the notion of the growth contagion (Weiss, 2004) between couples living with PD, which remains absent in the literature.

8.4 Summary

There were several clinical and practical implications of this study's findings. It is recommended that loved ones should be encouraged to attend psychological services, around the time of diagnosis and at critical junctures throughout the caregiving journey. Loved ones should be fully informed about potential positive and negative experiences that can accompany the PD caregiving experience, with the view to creating an environment conducive to growth-ful development during the PD caregiving situation.

The engagement with psychological services should ideally be with a mental health professional, who adopts an eclectic and/or integrative approach to therapy; utilising principles of positive psychology, ACT, and humanistic-existential psychotherapy. Psychological intervention should focus on enhancing adaptive cognitive skills such as identification and mobilisation of personal strengths, facilitating deliberate rumination, savouring the awakening experience, values clarification, fostering mind-ful acceptance coping, mindfulness reappraisal, and enhancing psychological flexibility. Development in these adaptive cognitive skills may bolster the likelihood of self-perceived psychological changes and growth-ful developments in the loved ones providing care; and ultimately improving their psychological well-being, and effectiveness as caregivers. This, in turn may have positive impacts on persons with PD.

Further research is needed to help appreciate the loved ones providing care experience of having, and caring for a person with PD. Research for better understanding sense-making, acceptance, and positive reappraisal should be considered because these remain under-researched areas. This research would build upon this study's findings, and

should be aimed at illuminating the cognitive and psychological processes implicated in self-perceived psychological changes and growth-ful development in PD caregiving.

The methodological strengths of this study were that it provided participants with an opportunity to reflect on the positive aspects of PD caregiving. The intensive qualitative phenomenological interview method had potential to enable participants to make-sense and ascribing positive meaning to their PD caregiving. This may have been beneficial to the participants and in turn their persons with PD. Participation in this research project presented an opportunity for participants to feel heard, validated, understood and included in research endeavours. However, this is only speculative and requires further investigation.

Future research should replicate this study to compare present findings with another sample. Moreover, future studies could adopt an IPA approach to investigate those loved ones providing care who do not report any positive psychological change and growth-ful development. Further research may use a cross-sectional design to compare and contrast loved ones providing care in various stages of PD, as well as widowed caregivers in order to track for similarities and differences in self-perceived positive psychological changes and growth-ful development between these samples. In addition, mixed-method, longitudinal research could address limitations of this study's cross-sectional design, and could validate and expand upon present findings. Finally, persons with PD should be included in future research endeavours, in order to triangulate and validate the caregivers' perceived positive psychological changes and growth-ful development, to overcome issues with self-report.

Conclusions and Contributions

Both the experience of having a loved one diagnosed with PD and the PD caregiving situation are associated with challenge, loss and compromise, but also holds potential for positive transformation and growth-ful development. Present study findings were consistent with other caregiving populations, such as loved ones providing care for family members with dementia (e.g., Farran et al., 1999; Netto et al., 2009; Sanders, 2005), early stage breast cancer (e.g., Weiss, 2004), other cancers (e.g., Manne et al., 2004; Moore et al. 2011), HIV (e.g., Cadell 2003, 2007; Carlisle, 2000) and stroke survivors (e.g., Bacon et al., 2009).

The qualitative nature of this study demonstrated ways in which caregivers can personally grow and develop as a result of having a loved one diagnosed with PD. The PD diagnosis is an experience that can represents not just a stressful, shocking or traumatic event but also a life-rejuvenating experience for both the caregiver and their families.

The findings revealed that loved ones providing care undertook a reflective transition by which they re-evaluated themselves, their outlook on life, their attitudes and their beliefs. They also reprioritised their values and the importance of their relationship with their persons with PD, their family and friends, and how they wanted to live their lives. Whilst it has previously been recognised in the PD caregiving literature that the PD caregiving experience can be stressful, burdensome and even traumatic; the PD caregiving experience also needs to be acknowledged as being a life-affirming and life-renewing experience. The PD diagnosis stands to awaken the loved ones and their persons with PD from an everyday mode of existence to an ontological mode of existence (Yalom, 2008), providing impetus to re-design and plan their lives, so life can be lived in the fullest, most positive, appreciative and meaningful way.

Findings revealed the internal struggles and conflicts that loved ones providing care can experience in the presence of PD. Loved ones struggled to make-sense of their

uncomfortable and distressing inner private experiences and underlying conflicts and initially expressed difficulty finding meaning in their personal situation. Loved ones grappled with existential conflicts such as mortality, meaninglessness, sense of responsibility and moral obligation to take on the primary caregiving role, and difficulty accepting the loss and unchangeable aspects of PD. Yet overtime the caregivers reluctantly accepted the uncontrollable aspects of the disease, and embraced a more positive and tolerant attitude to the ambiguous nature of the disease and their lives. The importance of acceptance throughout the caregiving journey needs to be acknowledged.

The nature of PD and the exact same circumstances where caregiving activities and tasks created everyday tension and strain also created moments of appreciation, and allowed for positive transformation and growth-ful development, such as becoming more patient and better at respecting another persons' boundaries and existential needs for autonomy, meaning and independence. Hence, it also needs to be recognised that the importance of developing patience, compassion, empathy, sensitivity and respect for a person with PD's existential needs and listening skills are required of loved ones providing care throughout the PD caregiving journey.

This study supports the shift from a negative to positive focus, and from a deficits-based perspective to a strengths-based perspective. In doing so, this study balanced out the pre-existing PD caregiving research and emphasised a more complete view of PD caregiving by demonstrating the positive side of caregiving. This study went some way to addressing the call for qualitative research to better understand the positive side of PD caregiving, and fulfil the unmet needs of PD caregivers who have previously expressed resentment for discussing the negative side of PD caregiving. Instead, this study awarded a sample of PD caregivers an opportunity to reflect on the positive aspects of caregiving which to date had been largely unexplored.

This study's interpretive-phenomenological approach offered novel insight into this area previously dominated by quantitative research, and enabled the subjective lived experiences and how they were positively making sense of their caregiving experiences to be explored in detail. Study findings extend previous caregiving research, which acknowledged that there can be positive aspects of caregiving (Blanchard et al., 2009; Chiong-Rivero et al., 2011; Habermann et al., 2013; Hodgson et al., 2004; Tan et al., 2012) by the use of influential psychological growth theories to explain findings. Such growth theories include the revised meaning-making model (Park, 2010), and the theoretical models of AAD theory (Papadopoulos, 2007), and PTG (Tedeschi & Calhoun, 2004) which assisted in gaining an insight into the psychological and cognitive processes that necessitate self-perceived psychological changes and growth-ful development.

The findings indicate that loved ones providing care employed a repertoire of meaning-making coping processes (i.e., searching for significance, searching for comprehensibility, benefit finding, positive reappraisal and so forth) to help them to make sense of their experience as a way of alleviating stress, distress or loss associated with PD caregiving. Through employing these meaning-making efforts, loved ones are able to regain or restore a sense of usefulness, purpose, worthiness and meaning, and enable them to maintain positive self-regard and positive beliefs about the self and the world (i.e., we're better off than others). This information gathered about the lived experiences of PD caregiving needs to be amalgamated into existing theoretical models and frameworks that are concerned with caregiving and adapted to PD. Furthermore, there was no one theoretical framework that could explain the self-perceived positive psychological change and growth-ful development associated with PD caregiving. Thus further research is warranted to develop a suitable framework.

The positive experiences varied over the course of PD caregiving, from the onset of the diagnosis to post-death of the persons with PD. This study highlighted the relevance of a longitudinal methodology and the ways in which PD caregivers not only adjust to unexpected difficulties during the early, middle and late stages of PD, but also develop new positive attitudes, values, appreciations, and behavioural and interpersonal skills across time.

The present study findings assist both researchers and clinicians to grasp the courageous and human qualities that make up the typical PD caregiving experience. They also stand to inform clinicians working with this population when designing psychological interventions. It is recommended that psychological interventions are designed to facilitate meaning-making coping processes (e.g., deliberate rumination, life re-evaluation and re-prioritisation, mindful acceptance coping, psychological flexibility, and positive reappraisal), for positive adaption and transformation throughout the caregiving journey.

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Appendix A: Flyer Advertisement

ARE YOU THE SPOUSE OF A PERSON WITH PARKINSON'S DISEASE?

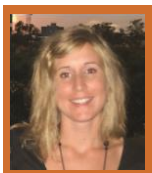
You are invited to participate in an exciting research project that aims to examine key factors that may buffer the burden, reduce stress and build resilience during the caregiving journey.

We understand that caregivers play a crucial role in promoting the quality of life and well-being of an individual with Parkinson's disease. Yet, commonly the carers' personal well-being is overlooked.

This project aims to gain knowledge about the caregiving journey, informing clinicians on how to develop programs that positively influence carers, by enhancing coping strategies and promoting emotional well-being in the caregiving role.

If you are willing, you can participate in this project by attending a brief one-on-one interview with the researcher, completing an anonymous questionnaire and/or attending a small group discussion with other carers.

It is appreciated that your time and energy may be limited; however, your participation and time are extremely valued. Efforts have been made to make your participation brief, yet rewarding.



If you would like to express your interest in participating in this project, please contact:

Deborah Worboys on 0404 860 164 or by email
djworb001@myacu.edu.au

Deborah is the student researcher and a registered psychologist.

She has both a professional and personal interest in PD and would love to hear from you.



Appendix B: Email Advertisement

Invitation to participant in report research project

Dear students and staff of ACU,

As part of the research component of my Doctorate of Psychology (Clinical) degree I am currently conducting research into the experience of care-givers who are the primary carer of a loved one with Parkinson's Disease.

If you currently care for someone with Parkinson's Disease I invite you to participate in this important research that will help to improve our understanding of the care-giving journey, and will potentially inform clinicians on how to develop programs and services that will positively influence the well-being of those in the care-giving role.

Participation will involve either attending a brief one-on-one interview with myself (at a mutually agreed location), completing an anonymous questionnaire and/or attending a small discussion group with other carers.

This research project has received formal approval from the University Ethics Committee (Reference number: Q2011 12)

If you are interested in participating or have any questions about this research please contact me:

Deb Worboys

Tel: 0404 860 164

Email: djworb001@myacu.edu.au

ACU Brisbane

School of Psychology and Counselling,

PO BOX 456,

Virginia, Qld, 4014

Please feel free to pass on my details to anyone you know who cares for a loved one with Parkinson's Disease. Much appreciated.

Appendix C: Persons with PD Demographics

Table A1

Persons with PD demographic information and PD characteristics

<i>Persons with PD demographic and PD information</i>		Phase One & Two	
		<i>n</i>	<i>%</i>
Gender	Male	23	71.88
	Female	9	28.13
Duration since time of diagnosis (years)	< 12 months	-	-
	1 – 2 years	2	6.25
	3- 5 years	8	25.00
	6 – 10 years	10	31.25
	11 – 15 years	7	21.87
	16 – 20 years	3	9.38
	20 + years	2	6.25
Estimated stage of the disease	Early	3	9.38
	Early to mid	1	3.13
	Middle	11	34.38
	Mid to Late	1	3.13
	Late	5	15.63
	Don't know	11	34.38

Note. Persons with PD were not included in the study; however demographic and PD

information about the participant's family member was collected. In both phase 1 and 2

combined, 23 were male and 9 were female. Ages ranged between 55 and 87 years ($M = 68$,

$SD = 8.88$). Duration of time since diagnosed with PD ranged between 1 to 23 years ($M =$

9.41, $SD = 5.75$). Three persons with PD were deceased.

Appendix D: Intake Questionnaire

PERSONAL DETAILS

NAME: _____

ADDRESS: Street: _____ Suburb: _____

State: _____ Post Code: _____

PHONE:

Landline: _____ Mobile: _____

EMAIL: _____@_____

GENDER: Male: ☐ Female: ☐ AGE: _____ yearsMARITAL STATUS: ☐ ☐ ☐ ☐
Single Married De-facto Other

PLACE OF BIRTH:

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Australia	New Zealand	UK	Europe	Asia	Other
			Please specify	Please specify	Please specify
			_____	_____	_____

What is the highest educational level you have achieved?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Primary	Some secondary	Secondary completed	Trade qualification	Tertiary level	Postgraduate

OCCUPATION: _____

How many hours do you work outside caregiving? _____ hours per week

Intake Questionnaire (continued)

CAREGIVING DETAILS

How long have you been caring for your family member? _____ years

During the past week, about how many hours have you spent providing care for your family member? _____ hours

Are you paid for your work as a caregiver: Yes: ☐ No: ☐

INFORMATION ABOUT YOUR FAMILY MEMBER

AGE: _____ years old

PLACE OF BIRTH:

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Australia	New Zealand	UK	Europe	Asia	Other
			Please specify	Please specify	Please specify
			_____	_____	_____

How long since your family member was diagnosed with PD? _____ years

Do you know what stage of Parkinson's disease your family member is in currently?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early	Middle	Late	Don't know

If so, what this stage formally diagnosed by a specialist? Yes ☐ No ☐

Appendix E: Interview Guide Phase One

1. Since (person with PD; family member's name) was diagnosed with PD, what would you say has been the hardest thing that you (and family member's name) have had to come to terms with?
2. In providing support or caring for (person with PD; family member's name), what is the most difficult/challenging thing you personally face at this time?
3. Do you think you have changed as a person as a result of caring for your spouse? If so, how?
4. What skills would you say you have acquired since becoming a caregiver? Have you found yourself doing things that you possibly have done if your spouse hadn't been diagnosed?
5. How has your relationship with (person with PD; family member's name) and others changed since taking on this caregiver role (or first diagnosed)?
6. How have you gained or grown since taking on this caregiving role? Or do you think you have grown or gained since you have been caring for (person with PD; family member's name)?
7. How has your philosophy/outlook on life changed since you took on this responsibility?
8. What are the personal qualities you have that have stood you in good stead for the caregiving experience?
9. If someone's partner was diagnosed with PD, what personal qualities do you think would stand that person in good stead?
10. Is there anything you wish you could change about your caregiving experience?
11. Hypothetically, if someone who had recently diagnosed with Parkinson's disease came to you, what would you say to them? What advice would you have for him/her?

Appendix F: Interview Guide Phase 2

1. How would you describe your experience since your loved one was diagnosed with PD?
2. In trying to support your loved one with PD, have there been times when you think you were particularly effective in providing support (either emotional, psychological or practical support)

(Prompt) Think back, and provide a specific example ... *What was the situation? What did you do? What did the (name of person with PD) do? What was the outcome?*

3. In trying to support your loved one with PD, have there been times when you think you were particularly ineffective in providing support (either emotional, psychological, or practical support), and thought " *I won't do that again*".

(Prompt) Think back and provide a specific example ... *What was the situation? What did you do? What did the person with PD do? What was the outcome? Knowing what you know now, what would you do differently if you had the chance?*

4. Imagine you had the opportunity to speak with a specialist, a PD guru who was "all knowing" in everything PD-related. What question(s) would you ask, and why?
5. Imagine there is a psychologist who has extensive knowledge about how best to support someone who is living with Parkinson's. What would you ask them? List up to 5 questions and state why they are important to you.
6. Imagine this psychologist developed a program, specifically for the loved ones of persons with PD, aimed at better supporting you and the person with PD. Would you attend that program? What would you expect to find in this program? When have you felt most needy of a program/support?
7. If both a professional psychologist and those living with PD developed a program, and the loved ones of people with PD were asked to deliver the program and facilitate workshops to loved ones recently diagnosed, could you see yourself wanting to deliver the program or facilitate workshops and sharing your experiences with others?

Appendix G: Ethics Committee Approval Letter



Human Research Ethics Committee

Committee Approval Form**Principal Investigator/Supervisor:** Dr Anne Tolan Brisbane Campus**Co-Investigators:****Student Researcher:** Ms Deborah Jane Worboys Brisbane Campus**Ethics approval has been granted for the following project:**

Turning strain into strength: Predictors of caregiver growth in spouses of individuals with Parkinson's disease.
 Positive and negative aspects of caregiving for a spouse with Parkinson's disease)

for the period: 9 May 2011 to 31 July 2013**Human Research Ethics Committee (HREC) Register Number:** Q2011 12**Special Condition/s of Approval**

Prior to commencement of your research, the following permissions are required to be submitted to the ACU HREC:

Parkinsons Qld, NSW, VIC, Tas, ACT, WA and New Zealand. Fox Trail Finder (part of the Michael J Fox Foundation)

The following standard conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (2007) apply:

- (i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
 - security of records
 - compliance with approved consent procedures and documentation
 - compliance with special conditions, and
- (ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
 - proposed changes to the protocol
 - unforeseen circumstances or events
 - adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than low risk. There will also be random audits of a sample of projects considered to be of negligible risk and low risk on all campuses each year.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.

Signed:

Date: 09.05.2011.....

(Research Services Officer, McAuley Campus)

Appendix H: Information Letter to Participants (Interviews)

TITLE OF PROJECT:	Positive & negative aspects of caring for a family member with PD
SUPERVISOR:	Associate Professor Anne Tolan
STUDENT RESEARCHER:	Miss Deborah Worboys
PROGRAMME ENROLLED:	Postgraduate higher degree Clinical Psychology

Dear Participant,

You are invited to participate in a Masters/PhD research project that examines both positive and negative aspects associated with caring for a family member with Parkinson's Disease.

What is the research about?

It is known that caregivers play a crucial role in promoting emotional, physical and the psychological well-being of an individual with PD. Yet, on many occasions the caregiver's personal well-being is overlooked. The aim of this research project is to examine key factors that may alleviate the burden, reduce stress and build resilience during the journey of caring for a family member with PD. Such knowledge may inform clinicians on how to develop caregiving programs to positively influence the caregiving experience, in terms of enhancing coping strategies and promoting emotional well-being in the caregiving role.

What we are asking you to do:

Participation is voluntary, and if you wish to take part you are invited to attend either a F2F or T interview with the student researcher. The questions are about your experience caring for a family member with PD, including the highs and the lows and the positive and negative aspects of caregiving. It is appreciated that your time and energy may be limited, although your full participation in this study is extremely valued. Efforts have been made to keep the interview brief, taking between 30 – 60 minutes. The interview will be audio recorded, with your permission.

If any of the questions lead to any feelings of distress or raise issues you would like to discuss with a professional counsellor, please contact:

Brisbane Psychology & Counselling Clinic (BPACC)
LifeLine

Phone: (07) 3623 7453

Phone: 13 11 14 (24-hour)

You are free to refuse consent to this study, without having to justify your decision, or to withdraw consent and discontinue participation in the study at any time without giving a reason. There will be no consequences for choosing not to partake in this study.

Confidentiality:

All data collected (e.g., audiotape and notes) during the interview are strictly confidential and will only be viewed by the researchers and then stored securely at the Brisbane Campus at the Australian Catholic University (ACU). The only instance where confidentiality will be breached is if there is risk of harm to the participant (e.g., risk of suicide) or to others. The data may be presented at conferences or in journal publications but all identifying data will have been removed.

Concerns & Complaints:

Any questions should be directed to the Supervisor or the Student Researcher:

Associate Professor Anne Tolan

(07) 3623 7256

ACU School of Psychology

PO Box 456 Virginia QLD 4014

Miss Deborah Worboys

0404 860 164

ACU School of Psychology

PO Box 456 Virginia QLD 4014

This research project has been approved by the Human Research Ethics Committee at the Australian Catholic University.

In the event that you have any complaint or concern, or if you have any query that the Supervisor and Student Researcher have not been able to satisfy, you may write to the Chair of the Human Research Ethics Committee (Qld).

QLD: Chair, HREC

C/- Research Services ACU

PO Box 456, Virginia QLD 4014

Tel: 07 3623 7429

Fax: 07 3623 7328

Any complaint or concern will be treated in confidence and fully investigated. The participant will be informed of the outcome.

If you agree to participate in this project, please sign both copies of the Consent Form, retain one copy for your records and return to the Student Researcher at the time of the interview.

.....

Deborah Worboys, Student Researcher

Appendix I: Consent Form



TITLE OF PROJECT: Positive & negative aspects of caring for a family member with PD

SUPERVISOR: Associate Professor Anne Tolan

STUDENT RESEARCHER: Miss Deborah Worboys

(Copy for Participant)

I *(the participant)* have read *(or, where appropriate, have had read to me)* and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in this study involving an audio-recorded interview, lasting 30-60 minutes, realising that I can withdraw my consent at any time. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT:.....

SIGNATURE:..... DATE:.....

SIGNATURE OF SUPERVISOR:..... DATE:.....

SIGNATURE OF STUDENT RESEARCHER:.....DATE:.....

Feedback:

If you would like to receive some general feedback about the overall results of this research project, please indicate: YES: ☐ NO: ☐

Please note that feedback will be given at the end of this research project, which may take up to 3 years to complete.

Appendix J: Information Letter to Participants (focus group)

TITLE OF PROJECT: Positive and negative aspects of caring for a loved one with PD
SUPERVISOR: Associate Professor Anne Tolan
STUDENT RESEARCHER: Miss Deborah Worboys

PROGRAMME IN WHICH ENROLLED: Postgraduate higher degree (PhD) Clinical Psychology

Dear Participant,

You are invited to participate in a PhD research project that examines both positive and negative aspects associated with caring for a loved one with Parkinson's disease (PD).

What is the research about?

It is known that caregivers play a crucial role in promoting emotional, physical and psychological well-being of an individual with PD. Yet, commonly the caregiver's personal well-being is overlooked. The aim of this research project is to examine key factors that may buffer the burden, reduce stress and build resilience during the journey of caring for a spouse with PD. Such knowledge may inform clinicians on how to develop caregiving programs to positively influence the caregiving experience, in terms of enhancing coping strategies and promoting emotional well-being in the caregiving role.

What we are asking you to do:

Participation is voluntary, and if you wish to take part you are invited to attend a small discussion group, which will include other loved ones of person with PDD. The group will run for approximately two (2) hours. The aim of the focus group is to gain your valuable insights and perspectives about your caregiving experience. The focus group will be audio taped.

If you agree to participate in this project, you will be asked to sign the enclosed consent forms, one for your records and the other for the student researcher. The Student Researcher will contact you in the near future with details about where and when the focus group will be held.

If any of the questions during the discussion group lead to any feelings of distress or raise issues you would like to discuss with a professional counsellor, please contact:

Brisbane Psychology & Counselling Clinic (BPACC)
LifeLine

Phone: (07) 3623 7453
Phone: 13 11 14 (24-hour)

You are free to refuse consent to this study without having to justify your decision, or to withdraw consent and discontinue participation in the study at any time without giving a reason. There will be no consequences for choosing not to partake in this study.

Confidentiality:

At the group, all attendees will be asked to respect other attendees' privacy and keep the information discussed confidential - *"what is discussed in the group, remains in the group."*

All notes taken and audiotapes from the group are strictly confidential. The information collected will only be viewed by the researchers and then stored securely at the Brisbane Campus of the Australian Catholic University (ACU). The only instance where confidentiality will be breached is if there is risk of harm to the participant (e.g., risk of suicide) or to others.

The data may be presented at conferences or in journal publications but all identifying data will have been removed.

Concerns and Complaints:

Any questions regarding this project should be directed to the Principal Supervisor and/or the Student Researcher:

Associate Professor Anne Tolan	Deborah Worboys
(07) 3623 7256	0404 860 164
ACU School of Psychology	ACU School of Psychology
PO Box 456 Virginia QLD 4014	PO Box 456 Virginia QLD 4014

This research project has been approved by the Human Research Ethics Committee at the Australian Catholic University.

In the event that you have any complaint or concern about the way you have been treated during the study, or if you have any query that the Supervisor and Student Researcher have not been able to satisfy, you may write to the Chair of the Human Research Ethics Committee

QLD: Chair, HREC

C/- Research Services Australian Catholic University

Brisbane Campus

PO Box 456

Virginia QLD 4014

Tel: 07 3623 7429

Fax: 07 3623 7328

Any complaint or concern will be treated in confidence and fully investigated. The participant will be informed of the outcome.

.....
Supervisor

.....
Student Researcher

Appendix K: Consent Form (focus group)



TITLE OF PROJECT: Positive and negative aspects of caring for a spouse with PD

SUPERVISOR: Associate Professor Anne Tolan

STUDENT RESEARCHER: Deborah Worboys

I (*the participant*) have read (*or, where appropriate, have had read to me*) and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to participate in this study by attending a small focus group, realising that I can withdraw my consent at any time. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT:

SIGNATURE DATE

SIGNATURE OF SUPERVISOR:DATE:.....

SIGNATURE OF STUDENT RESEARCHER:

DATE:.....

Feedback:

If you would like to receive some general feedback about the overall results of this research project, please indicate:

Yes ☐ No ☐ If yes, please provide contact details below:

Email:@.....

Postal address:.....

Please note that feedback will be given at the end of this research project, which may take up to two (2) years to complete

Thank you, your involvement is greatly appreciated!

Appendix L: Portrait of Participant

- ***Points of Contact:***

The first contact with Participant 2 was on Monday 22nd August 2011, when this individual contacted the Student Researcher by telephone after learning about the current research project at a DBS support group, and furthermore seeing the advertisement in the PQI Newsletter. Based on the information garnered at the initial telephone contact, Participant 2 was deemed suitable to partake in this research project as she fulfilled all the inclusion criteria. The information letter and consent forms were emailed to Participant 2 prior to the date of the interview. The interview was scheduled for Thursday 28th August, 2011, although she called to cancel the interview at the last hour, attributing to “being too busy,” and personal commitments. The interview was rescheduled to Thursday 8th September, 2011. The interview was conducted in the rooms of PPC Worldwide Pty Ltd, (a private psychology provider where the Student Researcher consults) on 8th September, 2011. It quickly became apparent that this individual was eager to gain as much information from the Student Researcher (e.g., knowledge from personal and professional experience, and what to expect in terms of the disease progression).

- ***Presentation at the Focus Group:***

- ***Demographics*** Participant 2 is a 62-year-old married author who was born in the United Kingdom. She achieved postgraduate level education.
- ***Observations (Including mini MSE)***
 - ***Arrival:*** Participant 2 arrived on time to the interview. She was dressed immaculately, wearing dark glasses. She was very well spoken. She appeared flustered on arrival. Whilst in the waiting room she spoke loudly on the telephone, seemingly organising another appointment. When she was greeted she disclosed she was trying to finalise the settlement of a property, which she described as “stressful” and stated that that was the reason she had been unable to attend the previously scheduled appointment, 2 weeks prior. She directed the interview from the onset. Favoured discussing her personal circumstances and quizzing the Student Researcher about her profession and personal experience with PD, the expected outcomes of the project, and what could be expected for her husband in terms of the disease progression rather than completing the necessary paperwork and signing consent forms. Permission to audio-record the session was not gained until the consent form was signed, so this data was not collected.
 - ***Mood & Affect:*** Participant 2’s mood appeared somewhat agitated. She became teary when discussing ... It seemed she was trying to evoke responses in the interviewer.
 - ***Concentration, Attention & Memory retrieval:*** Participant 2 appeared agitated, preoccupied and stressed. There were times during the interview when she lost her train of thought. An example of poor attention, possibly arising from stress was at approximately 10 minutes of interview, when she commented: “What was I saying? ... I’ve forgotten ... I’m stressed myself. So what was it about memory or something? Oh I can’t remember ...”
 - ***Attitude towards the researcher:*** She presented as an assertive and forthright individual. As aforementioned, she directed the interview from the onset. She appeared eager to learn as much

as she could about the PD caregiving journey and the progression of the disease. Extract from transcript:

IE: “Did it help me in the end? What are other caregivers saying?”

IR: “This is very new. You are only the third person I have interviewed. Um yeah.”

She reported, “knowledge is power.” This could be interpretive of adaptive ways of controlling situations, thus a way to manage underlying (and possibility dissociated vulnerability) insecurity and fear. Some of her responses were blunt. For example she remarked when responding to the question, “would you say there have been any highs as a result of your partner being diagnosed with PD?” She blatantly responded, “what an odd question!” Such responses evoked feelings of inadequacy in the interview that resulted in over-compensatory responses from the Student Researcher. For example, towards the end of the interview she challenged how this current research project may benefit the person with PDD. It was of note that she interrupted the interviewer on numerous occasions. Although she appeared to have insight that she was doing this and that it may have a negative impact on the recipient.

- *Attitude towards their loved one:* One of her biggest current struggles appeared to be the deterioration in the relationship with her husband. She appeared to have an idealised image of her husband and their relationship prior to the DBS surgery. This was congruent with comments made by a PD nurse, who suggested that Participant 2 might have an idealised image memory of her husband and their relationship prior to the DBS. Participant 2, however, adamantly disagreed with the nurse’s reflections. She commented at approximately the 15 minute mark:

I got the impression from one of those nurses ((mocking)), one time, I can’t remember the way she described it, I can’t remember the words, but the way she described it was like I was exaggerating the happiness of our marriage and then obviously making this comparison.

- *Beliefs, Assumptions, Schemas:* She described herself as clever and strong-minded. She believed in acquiring knowledge and using it to her advantage. She commented, “knowledge is power.” Based on descriptions about her fear of getting married and losing another loved one (like she lost her parents). Seemingly she has maladaptive abandonment schemas.
- *Future Orientation:* She appeared hopeful for the future, seemingly in light of the most recent improvements in her husband’s condition and hence the quality of their volatile relationship, as she described it.

- ***Caregiving Experience:***

Participant 2 reported that his wife was diagnosed with PD for 5 years. She perceived that she had cared for him since he was diagnosed. She stated she would fetch things for him and organise things at home. She reported that since the DBS surgery, he no longer required her help, she felt pushed away and excluded (push and pull traits – could be linked to attachment history and personality characteristics of Participant 1). She

reported that she was no longer invited to specialists appointments and described not feeling apart of the management process of her husband's PD condition, journey and ultimately his life

- ***Initial Analysis & Interpretation:***

- ***Themes*** (e.g., *What were the main themes or issues in the contact? Which research questions did the contact bear most centrally on?*)

- ***Caregiving Struggles***

- Husband's denial and refusal to learn about PD, and attend support groups.
- Not knowing what to expect, "Knowledge is power."
- Frustrated by comments and somewhat vague generalisations from the specialists, "everyone is different, a unique disease."
- Perceived lack of support from husband and treating professionals.
- Lack of opportunity to speak with the specialists 1:1 in the absence of the Pw PD.
- Dealing with the aftermath of the DBS.
 - Perceived husband to be lacking in warmth, affection, inclusion.
 - Resulted in relationship breakdown.
- Co-morbidities – person with PD – alcohol dependency.
- Perceived lack of collaborative approach from the specialists and nurses.
- Feeling that LOPC is not involved in the treatment/management of the disease.

- ***Caregiver coping strategies (positive)***

- Researching medical literature and acquiring knowledge.
- She believed that courage, and guts "to go the distance" is required, as well as patience, energy and understanding of the disease.

- ***Caregiver coping strategies (negative)***

- Tendency to want to control all situations, protect him, prevention of embarrassment, "protect his ego" in social situations. Needs a protector?
- Believed she could pre-empt her husband's needs and provide care. Although he is seemingly refusing any help. Look up the aftermath of the DBS – improved functioning, properly doesn't require help – links to some literature about the loved one not coping with not being needed as much after DBS. Both individuals' roles need to be flexible in the relationship, and evolving.

- ***Support***

- A fabulous friend, but no family support.
- Some support from the social worker at the hospital. She asked the social worker to communicate with Specialists in the hope of being more involved with treatment.

- ***What new hypotheses, speculations or guesses were suggested by the contact?***

- She denied growth or any positive changes as a result of the diagnosis.

- **Poor Quality of Relationship & Insecure Attachment Style** – likely to impact coping. Both parents died, she was concerned about marrying and being left. Themes of abandonment. Based on presentation and self-report there was some evidence of BPD traits. Fear of abandonment – resulting in adaptive manipulative, controlling tendencies (as a prevention) but ends up pushing others away (husband, specialists and me when she offered to help at the end of the interview – I wanted no further contact).
- Seemingly co-dependency issues – did her husband help to regulate her emotions, and currently given the physical, psychological and cognitive limitations that arise from the disease, and in this case the aftermath of the DBS?
- **Good Quality of Relationship** – in this case rather than the (good) quality of the relationship prior to the Dx positively influencing the couple – in this case it seems to have been a negative factor. Although this could be an extreme case.
- **Wanting To Know What to Expect: a thirst for knowledge to quench anxiety** – she described feeling left out (excluded) of her husband's journey – could be related to abandonment schemas or personality traits? Ignored by specialist and PD nurses (again could be related to personality traits of this individual). She researched on the net. Relies on self, rejecting other's help? She described herself as a clever and strong-minded person, who is well educated. Like Participant 5, (also well educated and previously was a nurse) they find it frustrating that specialists talk in vague generalisations. Whereas others seemingly find comfort in "uniqueness of the disorder" especially when others' symptoms are worse off. Is there a difference in people? Or is it just a case of we make situations suit ourselves for our own ways of coping – defense mechanisms?
- Participant wants a one-on-one with specialist – positive or negative – look up the research. Speculation/interpretation: it seems the more intellectual the person the more troublesome for the specialist? – link to dementia caregiving (Leipold et al., 2006) found the more intelligent, the more cynical, less likely to employ meaning-making processes and report growth. This participant is an author, completed post-graduate education, and didn't report growth. Seems to fit with Leipold's study findings and conclusions.
- There was a sense of displacing anger onto the specialists and nurses. Safer or easier to blame.
- There was a sense of idealisation of the relationship prior to DBS. Stated never argued, now argue every day. When to couples never argue? – Dysfunctional in itself, maybe he was more tolerant in the past.
- **Unexpected themes / Surprises?** – look up research about the aftermath of DBS and impacts on both the person with PD and their loved ones.

Reflection of Practice

I felt intimidated and apprehensive from the onset of the interview. I felt that I was being used for functions of the interview (e.g. as a source of knowledge). At the termination of the interview, I felt my head was spinning, and I was somewhat unnerved by this encounter. I felt kind of “shell-shocked,” and had to reflect on interview, make some notes, gather my thoughts prior to conducting a scheduled counselling session following the current interview. I was still thinking about the interview when I met a friend for a movie that evening. And even expressed that I had experienced an encounter with a challenging individual, and more formally debriefed with my supervisor during the week that followed. During the interview I felt I was being drawn into assuming many roles for the participant, for example, a reassurance provider, a validator, a soother, a counsellor, a specialist, and a student/novice.

Given her presentation, self-report, and the counter-transference experiences, the data collected from this interview, should be interpreted accordingly and with caution. This participant was considered an extreme/negative case.

Appendix M: Participant Mind Map

Figure A1. Participant Mind Map

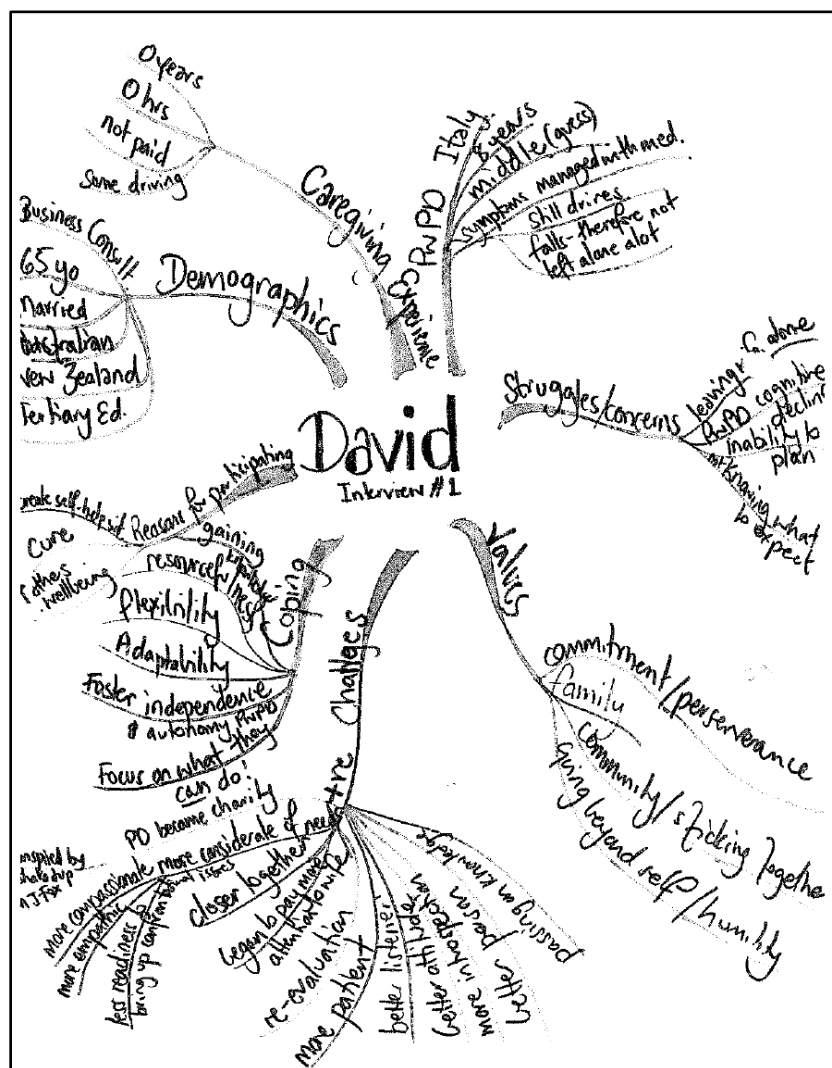


Figure A1. Visual mind map of participant. Mind-maps were developed during stage one of the analysis. The development of a mind map for each participant served as an aide for the researcher in immersion and familiarization with data, as part of the preliminary analytic tasks. Each mind-map provided a visual holistic and contextual representation of each participant. The mind-maps included background information and demographics, caregiving experience, as well as initial thoughts, ideas, themes, and early interpretations generated from process of “active” reading phase of the analysis. These visual maps were repeatedly referred to during the phases of analysis, in order for the researcher with re-familiarisation of each participant.

Appendix N: Transcription Conventions Key

Table A2

Transcription Conventions Key

Symbol	Description
IE	Interviewee
IR	Interviewer
(.)	Just noticeable pause
...	Indicates that a few words – less than one line of text – have been removed from the transcript (does not indicate a pause in the conversation being transcribed)
(...)	Three dots between brackets indicate that some material, more than one line of the original transcript, has been omitted
(...)	Four dots between brackets indicate that more than a few lines has been omitted
(())	Double parentheses indicate the transcriber's descriptions of talk or behavior, such as ((laughter)) or ((coughs))
[]	Context information. For example [person with PD]
//	Double oblique indicate a point at which a current speaker's talk is overlapped by another.
<i>word</i>	Emphasised words
<u>word</u> WORD	Underlined sounds are louder, capitals louder still
<u>wor-</u>	A dash shows a sharp cut-off
(inaudible)	Unclear talk.
.hh, hh.	in-breath (note the preceding full-stop) and out-breath respectively.
wo(h)rd	(h) is a try at showing that the word has “laughter” bubbling within it
.	Final sentence or falling type of falling intonation at end of phrase
?	Rising intonation at end of phrase
!	Intonation of surprise or forcefulness at end of phrase

Note. Transcription conventions developed by Gail Jefferson for conversational analysis

Appendix O: Extract of Transcription

Interview Transcript

Date held: 13th September 2012
 Location: Telephone Interview
 Time: 1.30pm
 Attendees: Deborah Worboys – Researcher/Interviewer (Speaker 1)
 DB (Alex) – Participant (Speaker 2)
 Interview Duration: 50 minutes

0:00:00 Speaker 1: Tell me a about your PD journey

0:00:05 Speaker 2: Well, it's been probably... well it took a little while for diagnosis, we went round about to GP to neurologist to rheumatologist, and another physician and then the diagnosis was made finally by a neurologist, so it was sort of a bit torturous and traumatic even getting a final diagnosis. We knew something wasn't right and she was unwell, well not unwell, but there were some issues happening with her, just general life, balance and movements and pain and a whole host of things. So I suppose from that point of view it was sort of torturous and fairly difficult, and finally the diagnosis was made but it's a bit of a bolt, you know, hitting you. I mean by that time we had thought it was MS and other diagnosis but I know Parkinson's disease and the Parkinson's spectrum of diseases is somewhat difficult to diagnose. But I mean, from then on in it - my wife was, she's also a Dentist – and she was actually doing her PhD in research and she struggled on with it, but then was advised by her neurologist to cease the research because it was causing too much stress for her to continue doing it.

0:01:38 Speaker 1: Yes... (cross talk)

0:01:38 Speaker 2: Which caused a huge amount of angst on her part. Mentally I felt that she was and she still is quite alert, and wit, and vibrant mentally. And erm, I suppose that loss of that research was really sad and that was a really difficult thing for her,. But watching her have to give up that was very difficult and I suppose watching her as her husband just deteriorate over the years since 2009 diagnosed, fairly advanced. But she used to paint and just watching her transition of her painting, the art that she in 2000 through to now is significantly different where her motor skills have deteriorated to the extent that she's had to give up painting, which again is really sad. And she used to give little speeches at the art gallery down here as a gallery guide, well she can't speak so well anymore because no one can understand her, so she's given that up. So all the little things in life, her work, she's had to give up, her art she's had to give up, her gallery guiding she's had to give up. But she struggles on with life, I must admit I'll hand it to her, she's an incredible women, the way she managed the deterioration that's occurred over the last four years. I don't think I'd be able to do that at all, so I think watching her

battle with the disease and lose those little pleasures of life disappearing has been hugely sad, just horrible for me to watch. But on the other hand very uplifting to see how she handles it, hugely admirable. And I suppose that the other thing that I find really difficult as a partner and becoming the principally the primary carer, I mean I still work but I go into work late so I don't go into work till 10 o'clock till about 3.30 normally, and I have carers in the middle of the day, so there's a lot of personal care that I do in the morning and at night, and during the night. I suppose the move from husband and loved one, a spouse, into a carer role and a lot of tasks and functions for her and keeping her safe and she's a significant faller, she has a lot of falls. I find that balance between being a husband and the emotional side of it and the love side of it and balance that with being the primary carer, sort of putting on the blinkers and saying we've got to keep her safe and I've got to do the washing and the cooking, the personal care and the hygiene and the whole bit. I find that balance very difficult to manage. Being a clinician, I sort of go into that clinical mode, where I treat her more as a patient, and she doesn't like that, she's told me she still sees me as her husband, and she feels she's lost me as a husband, and I don't like hearing that. She says that quite often, that she's lost me as a husband, she says 'You're an exceptional carer and I feel very comfortable and safe when you're around but I've lost you as a husband', so you're more a carer friend than a husband, and I'm trying to work on that, maybe I'm not very good at it. But that's probably one of the significant things that I--- the actual caring I don't mind at all,

0:05:57 Speaker 1

Yes (cross talk)

0:05:57 Speaker 2

I feel confident and comfortable managing it. All levels of care, from personal care, like dressing, to fully managing to that level, and I like that doing for her, and I suppose it's a bit of a slap in the face for me; 'Yes David you're very good BUT we've lost emotion and that love part of it', I mean I'm still loving, but she feels she's lost a husband and gained a 'carer'. And I think that's difficult for me to handle and that's the difficulty that I'm struggling with at the moment.

Carers come in and work with her, and I sometimes think 'Oh gosh, if carers come in and do all the work I do then I can continue being a husband, if I had a carer for you 24/7 Rosemary I could still be your husband and the emotional and the loving and the lover, support and the carers could do all the caring'. It would be much easier for me, (laughs) I wouldn't have to do that that part,

0:07:05 Speaker 1

Switching between roles, yes!

0:07:05 Speaker 2

I wouldn't have to switch from one role to the next, but that's the significant things that I'm struggling with at the moment.

Appendix P: Extract of Journal Log

13/06/2013 11:51 AM

Continuing to code the focus group.

Themes - growth

--CG had to learn to stay calm (doesn't help PwPD if a hot head) - go back and code participant 1

--CG had to learn to be more emotional (states he's a typical male not demonstrative of emotions - same as Participant 13.

--learning to anticipate and provide for emotional needs

Not only a struggle to know the line or boundary about how much help to provide, but what type of support is required (e.g. emotional - and males struggles more so with that).

Again relates to psychodynamic approach of people not being able to identify and fulfil their own needs, thus look to another to fulfil. Attachment styles.

Participant 1 from focus group is stating how he had to learn to show emotional empathy ---- (is the PwPD feel unloved) - does this relate to or overlap with Participant 32 and how he also reports that the PwPD complains she has lost her husband, and gained a clinical carer.

But everyone is different, Participant 2 from focus group is describing how her husband is a new-age, sensitive guy.

Modified node at Struggle:

LO had to slow down, doesn't watch, and allows more time, walk away -- added hold off, watch what say

She is careful not to throw his life into chaos - but trying to do too much at once (on her list) he can't with too much information at once

LO has to be careful not to overload the PwPD - gets anxious -- can't think straight ---- stresses him out... --- another caregiver reported fading out.

Second coder:

Communication as a standalone Symptoms - whereas I coded at Change in relationship and over laps with the way we interact

Relationship Changed/The way we interact/more withdrawn, would expect more cheery interactions Modified to more withdrawn, doesn't initiate....

Theme about the female LO pushing the PwPD to do things, although this is a natural trait in relationships.... and couples counselling, female wants to do more, and complains about having to initiate everything. Thus issues magnified in the relationship.

PwPD rather not go out, rather people didn't see him - links to more self-conscious and anxiety

Theme PwPD does like to go out as much... LO pushes... male thing?

Solitary tasks, read, paint, potter, computer, stocks and shares -- solitary, introverted tasks

Although others love to be out.

Numerous nodes at LO had to change for the relationship to survive:

More understanding of PwPD limitations

Introspection and self-analysis

I look at things in a different way to how I once did

I had to Tone things down

I had to Change my Attitude

I had qualities that weren't very nice or pleasant. I wasn't an angel
 Develop some self-control
 Short fuse, would take a lot to fire up.

Overlaps with focus group - Personality hot headed, had to learn not to fly off handle, calm, manage,
 Modified by adding tone things down, develop some self control,

If LO upsets PwPD or makes a mistake, willing to correct or change behaviour - overlaps with had to change for the relationship to survive --- consider a themes for willingness to change (or accepting influence from partner - Dr John Gottman) to improve the quality of the relationship...

LO goes bike riding, soaks in --- similar to the concept 'savouring' - finding the sweetness in life/

PwPD may appear withdrawn, bored or disinterested, LO has to explain... coded at difficulty sleeping but should be coded elsewhere... come back to it in clean up.

Participant 1 is describing "anyone who is caring for a loved one with a degenerative disease or progressive illness, whether it be Parkinson's anything else will need psychological support to deal with the mental issues that arise from the emotional burden that comes with watching your loved one or the person you married deteriorate, or fade away."

Modified node: main problems with caregiving/not easy to watch loved one deteriorate to emotional burden, watching love one deteriorate, fade away

Isolation and seclusion - on own a lot.

Double codes at Medication ---- antidepressants - refused AND sought counselling, recommended anti-depressants, research refused.

Participant 3 of focus group is also saying that its as important to pass information on to others as it is to gain information from the support groups, coded at... share information, ideas and be positive for others.

"It's not just what the support group can do for you, but what you can do for the support group - fits with the LO (and PwPD) feeling they need to do something..."

14/06/2013 3:13 PM

Continuing to code the focus group, also stating that they don't know what to expect - participant 2 reported it's in her personality to know what to expect - coded, need to go back and recode. Finding lots of codes whereby too specific and only got one reference so making, deleting and merging nodes, making them more generic, thus reducing the number of nodes.

Another theme in the focus group that supports themes in the interviews is that people don't know what to expect, what to look for, how to cope, what the future holds...
 Thus forced to take things day-by-day - no long-term planning.

Although I think the values exercise, 'gravestone' could be a power intervention... act my values regardless of the journey. Thus gives some sense of control. It's the ego that wants to know...

There appear to be mixed views of seeking psychological intervention

Appendix Q: Mechanics of Initial Code Generation

Table A3

An example of generation of initial codes from transcript

Speaker	Data Extract:	Coded at:
IE:	Since she (his wife) has been taking the medication it has returned her to normal life functioning, so she really does not need a lot of [help], if any help. So, erm. I don't know really what you want me to put there? [interviewee is completing the section of the demographic questionnaire that pertains to caregiving characteristics]	Care for person with PD //Since taking medication returned to normal functioning Care for person with PD //Since taking medication returned to normal functioning/doesn't need much help, if any
IR:	((No response - Silence))	
IE:	She hasn't really needed any care there, she still does a lot	Care for person with PD //Since taking medication returned to normal functioning/doesn't need much help, if any/person with PD still does a lot
IR:	In that case we don't need to fill that in [pointing to question on intake form]	
IE:	And the other one [referring to another question on demographic question] "How many hours do you spend caring for your spouse?" [reading from the questionnaire]. See I don't. See Maggie [wife, person with PD] is pretty good, I don't have to do much for her at all. Unless she does not feel like driving a car ... then I do that for her. So those are the things she needs me there for, but other than that ... Erm/	Care for person with PD //Transportation person with PD drives to the shops Care for person with PD //Transportation//person with PD does feel like driving, LOperson with PD drives

Note. IE = Interviewee (Participant 1, Darren); IR = Interviewer/Researcher; PwP = person with PD; LOPD = loved one of person with PD; // = a function in NVivo that distinguish level of codes; (()) = non-verbal communication (see Appendix O for transcription conventional key).

Appendix R: Mechanics of Reaching Coding Consensus

Table A4: *Mechanics of reaching coding consensus.*

Transcript	1 st Independent Coders Coding	Researchers Coding	Codes as a result of reaching consensus
IE: Parkinson's is a bit like that. The other thing is. Because Parkinson's comes upon you and you are not prepared for it. You don't marry someone because you think in 30 years' time, they will get Parkinson's. So you are thrown into a caregiving role. Um without any experience or knowledge. And you then have to face it in a certain way, and the way// IR: No prior training IE: I face it, is I try not to take too much responsibility from Maggie [person with PD] because it is important that she looks after herself. So it's important that you are there when you are needed, but you do not want to interfere with the other person's life//	Care for spouse or person with PDD\don't want to take their independence away stand back and let the person with PDD do things	Care for person with PD\maintaining person with PD independence\don't take away independence\stand back and let them to things	Care for person with PD\important to maintain person with PD independence\don't want to take away independence, stand back let them do things
	Care for spouse or person with PDD\if something can't do, need to find something can do, something else to do	Changes in person with PD, effects of the disease\Translate interests in to another, area find something else to do, rather than give up	Changes in person with PD, effects of the disease\Translate interests in to another, area find something else to do, rather than give up
	Care for spouse or person with PDD\person with PD translated interest to another area		
	Care for spouse or person with PDD\important to look after them-self	Care for person with PD\important to be independent\important for person with PD to look after themselves	Care for person with PD\important to be independent\important for person with PD to look after themselves
	Care for spouse or person with PDD\important there when needed, not to interfere with their life\important to achieve a balance, don't want to take over their lives or away responsibility	Care for person with PD\important for person with PD be independent \ be there if needed, without taking away responsibility or interfering	Care for person with PD\important for person with PD be independent \ be there if needed, without taking away responsibility or interfering
	Care for spouse or person with PDD\pace yourself	Care for person with PD\pace yourself	Care for person with PD\pace yourself

Note. // = interruption/cross-talk (see Appendix O for transcription convention key); IE = Interviewee; IR = Interviewer; person with PD = person with PD, in this instance participants' wife who was present at the interview; \ and \ = function in NVivo, distinction between level of codes; LO = loved one providing care; PD = Parkinson's disease; person with PDD = person with PD.

Table A4 (continued)

Mechanics of reaching coding consensus.

Transcript	1 st Independent Coders Coding	Researchers Coding	Codes as a result of reaching consensus
<p>person with PD: There are people who need to look after themselves</p> <p>IE: That's true.</p> <p>PwP: But you don't want to take their independence from them, as they need something to do. To fulfill their day.</p> <p>IE: But the vast majority of people with Parkinson's, they need to be able to manage what they are going through, and to manage their lives for themselves. So if there is something that they can't do then, they need to find something they can do, and find something else for them to do.</p> <p>IR: to have a sense of independence and a sense of meaning, in their own life.</p> <p>PwP: Yes you need to have something to do for the day when you wake up in the morning.</p>	<p>Care for spouse or person with PDD\need something to do to fulfill their day</p> <p>Care for spouse or person with PDD\need to be able to manage what they are going through, manage their own lives</p> <p>Parkinson's comes upon you and you are unprepared for it, thrown into the caregiving role</p> <p>Parkinson's comes upon you and you are unprepared for it, thrown into the caregiving role\without experience or knowledge</p> <p>Parkinson's comes upon you and you are unprepared for it, thrown into the caregiving role\you have to face it</p>	<p>Care for person with PD\maintaining person with PD independence\ need something to fulfill their day</p> <p>LO unprepared for PD\thrown in to the role</p> <p>LO unprepared for PD\thrown into the role\no experience or knowledge</p> <p>LO unprepared for PD\thrown into the role\forced to face it</p>	<p>Care for person with PD\important for person with PD to be independent/need something to fulfill their day</p> <p>Care for person with PD\important for person with PD to be independent/need to be able to manage what they are going through, manage their own lives</p> <p>PD comes upon LO, LO unprepared for it\thrown into caregiving role\</p> <p>PD comes upon LO, LO unprepared for it\thrown into caregiving role\without experience or knowledge</p> <p>PD comes upon LO, LO unprepared for it\thrown into caregiving role\forced to face it</p>

Note. // = interruption/cross-talk (see Appendix O for transcription convention key); IE = Interviewee; IR = Interviewer; person with PD = person with PD, in this instance

participants' wife who was present at the interview; \ and \ = function in NVivo, distinction between level of codes; LO = loved one providing care; PD = Parkinson's disease; person with PDD = person with PD

Appendix S: Mechanics of Theme Generation

Table A5

Mechanics of theme generation from initial codes

Nodes (initial codes) and sub-nodes (or sub-codes)	Sources	Refs
Brings us Closer together	13	25
learning things together	4	4
talking through things, feelings	6	7
working things out, facing things together	4	6
Relationship strengthened since PD, made us stronger	12	39
admiration/appreciation for person with PD strengths, not giving up, continuing to do things	4	8
always respected person with PD but now there was other dimension	1	3
arguments less frequent, mellowed	2	2
better at putting things into perspective, dealing with differences of opinion	1	2
Done more together	4	6
Cycling	1	2
Developed shared interest	1	2
Sailing	1	2
Exercise,	3	5
More comfortable together	1	2
work better as team, know how the other one thinks, better at know what they want	3	8
LOPD come to know person with PD better	2	5
We laugh more	4	6
Our family has always been close, we're closer now	6	9
a network of friends on same journey, call upon when needed, offers relief	1	1
at group we talk about funny things, make each other laugh, we're like family	1	4
closer to mother, seen softer side, in past at logger heads	1	1
Faith is important, brought us closer to god	1	1

Note. Sources = number of participants; Refs = number of times referenced across entire dataset. This table shows an export from NVivo 10 of the initial codes that were grouped together, and went on to form the master theme three “Relationship Growth,” and sub-themes 3a “Closer to person with PD” and 3b, “Closer as a Family” (analytic phase 5). Some of the codes did not remain here, and at subsequent analytic stages through process of refining and redefining themes (analytic phase 4) were moved to another theme, where it was deemed by researcher they fitted better. For example, sub-codes such as “admiration/appreciation for person with PD strengths, not giving up, continuing to do things” and, “always respected person with PD but now there was other dimension” were moved to the Master theme 1 “Positive changes in on living,” and sub-theme 1a “becoming more grateful through social comparison (analytic phase 5).

Appendix T: Thematic Maps

Figure A2. Initial Thematic Maps

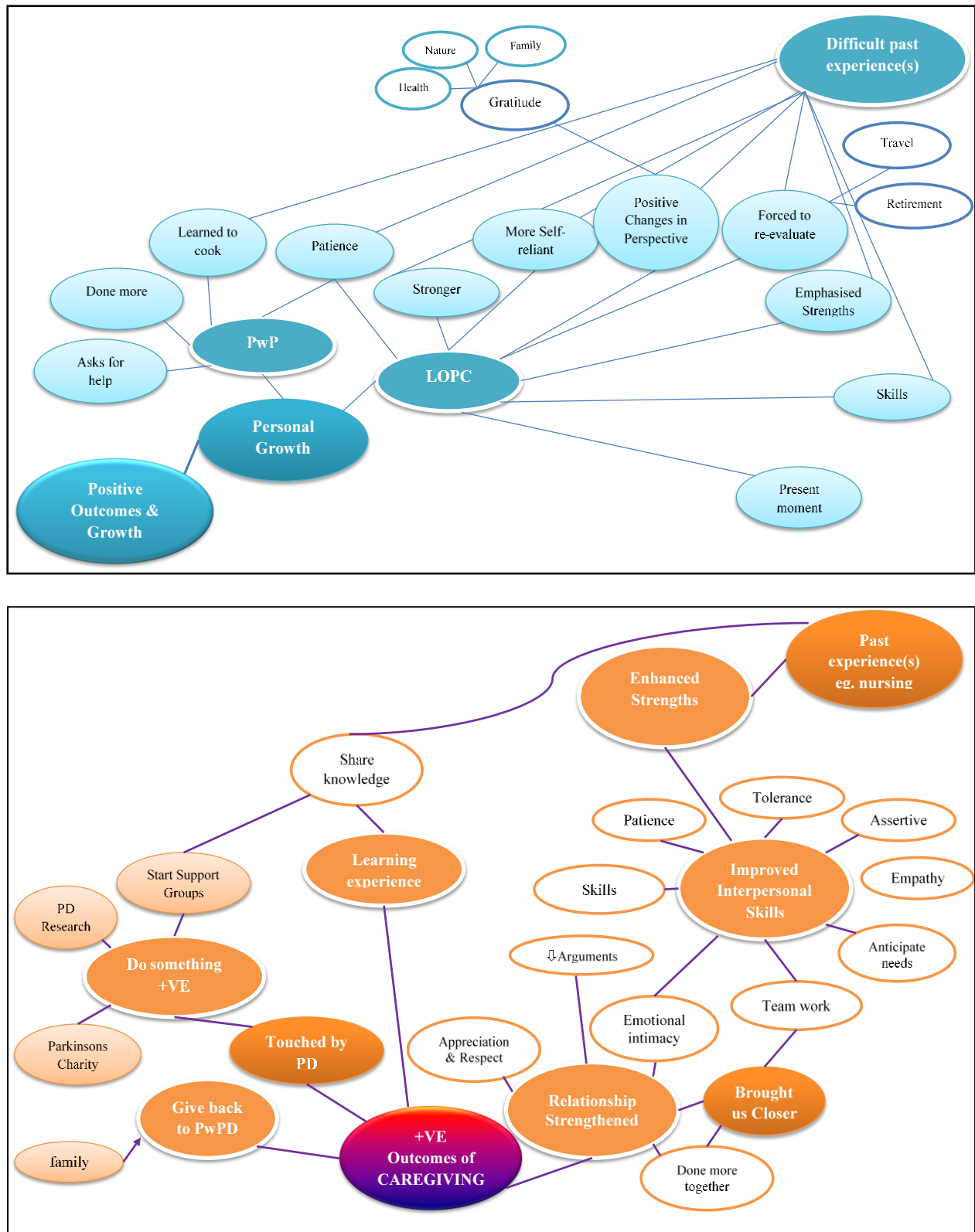


Figure A2. Thematic maps were developed to assist researcher in phase three 'generation of themes' phase of the analytic process

Appendix U: Reflections of Practice

The purpose of this section is to demonstrate the reflexive nature of this study. This appendix includes reflections about choosing this particular research topic, choosing a methodology, reflections of practice during data collection and the analysis. This appendix is written in the first person because it comprises of the researcher's reflections throughout the research process.

The chosen project

I consider myself to be a growth-motivated individual with a bent for both personal and professional growth from any project(s) I undertake. I am constantly working toward self-actualisation. I strive to be the best version of myself. I have been exposed to adverse events. For example, the death of young friends to leukaemia, a brain tumour and cancer; watching my grandfather as he lived with the adversities of PD; witnessing my grandmother deal with challenges associated with providing care for my grandfather with PD; and subsequently seeing my grandmother's longstanding grief as a result of my grandfather's passing. I have spent time reflecting on these adversities, and as a result ascribed positive personal meaning to these adversities. I am aware that my personal way of coping is to, "find the gold in the garage." I attempt to find positive personal meaning and patterns in life to help me deal with the uncertainty and ambiguity of life, and to provide a sense of security and control.

I acknowledge that I have positively reframed the reasoning for my grandfather having PD, which undoubtedly shaped my decision to engage in a research. It brings both me and my family comfort that I am investing time and energy into people directly and indirectly affected by PD. I draw upon my personal experience of when PD was present in our family and its impacts, and endeavour to do something positive for others affected by PD. I draw comfort from the belief that there is something bigger than me, and that I was put on this

earth for a reason. I see this research project as a way of finding meaning for my grandfather having PD, and the devastating impacts on my family. It gives me a sense of purpose and a sense of meaning. Through forging meaning it has given me strength, determination and courage to drive me, and kept me going enough in times when I thought I could not complete this thesis. Nonetheless, when embarking on this project I had no professional experience with the loved ones providing care for PWP, nor PWP. Rather, in the spirit of phenomenology, I had a curiosity and a willingness to learn from those who know best, those who have expertise in this area, that is, the loved ones of persons with PD.

The chosen research and methodological approach

For any researcher embarking on a research project, it is recommended that not only does the research topic need to appeal to them, but it is also desirable that the way of researching the topic also fits with the researcher. Etherington (2004) asserts that it is advantageous for the philosophical underpinnings of the chosen methodology to be suited to the philosophies and beliefs of the researcher.

When setting out on my research journey I needed to find ways of working and researching that fit with who I am. My personal values, my philosophies on life, my views of reality and my beliefs about how knowledge is known and created. My view of reality or the nature of being or what is (ontology), and my understanding of what it means to know (epistemology) are intertwined. I do believe that the world exists out there independently of our being conscious of its existence. I agree with philosophy of phenomenology that “the world becomes a world of meaning only when meaning-making beings to try to make sense of the world (Etherington, 2007, p. 71).

Like the theoretical and philosophical assumptions underpinning IPA, I too believe reality is socially constructed and subjectively determined (Willig & Stainton-Rogers, 2008). This means that the methodology used in this project needed to be suited to the purpose of

discovering an element of how those constructions came about and the meanings that people give them. Etherington (2004) maintains that choosing how to do research is therefore a researcher's personal decision about what they need to do to discover what they want to know. In my case, there were several existing methodologies that suited my needs, and for the purpose of the project that I was undertaking.

At the beginning of this research project, I had minimal experience in the application of qualitative research methods, especially IPA. Notwithstanding this methodology appealed to me. I prefer to work directly with people. Qualitative research method is my preferred personal research method. Qualitative researchers are required to immerse themselves fully in the participant's psychological world, adopt an attitude of informed curiosity, and constant careful receptivity and self-reflection (Smith & Eatough, 2012). This is consistent with my personality and preference for working with directly with individuals. Rather than quantitative counterparts whose methods require detachment, control and prediction (Smith & Eatough, 2012). The epistemological and ontological positioning, as well as theoretical and philosophical underpinnings of IPA, are congruent with my beliefs about my views of reality and my beliefs about how knowledge is known and created.

Furthermore, IPA suits my theoretical frameworks that I adopt in Clinical Practice. I adopt an integrative approach to therapy, tailoring therapeutic approaches and interventions to client needs. I am not wedded to any particular therapeutic approach. But I feel most affiliated with brain-based, psychodynamic, humanistic-existential, and acceptance and commitment therapy approaches.

My biggest challenge in therapy is practising aligned with principles of phenomenology, and bracketing my own preconceptions, presuppositions and judgements, and not imposing my own beliefs and ideas onto the client. For example, what I think about the client, who they are, and what they should be feeling or doing. Rather, demonstrating

unconditional positive regard and adopting an attitude of curiosity, acceptance and openness to whatever the client, or in this instance the research participant presents. And moreover, having the courage not to hide behind the role of the expert, from a position of knowing, rather having conviction that the client has the answers and solutions to their presenting concerns, and that it is my role to tap into their inner world, to make the implicit, explicit; to reveal the concealed; to tap into the client resources, so they leave the therapeutic encounter feeling empowered, rather than dependent on me or another therapist to fix them; and ultimately promote a growth experience for the client and assistance in self-actualisation. Rather than using therapy or the role of a psychologist to bolster my own self-esteem through being “helpful” or a good therapist and solving the clients’ problems.

In addition, IPA awarded the opportunity to be touched, taught, encouraged, inspired, and shaped by participants. This research endeavour is likely to shape my future career if I am successful in gaining an opportunity to work with families who are affected by PD. I have a keen willingness to learn about research, PD, PD caregiving, and myself. I am open to be influenced by the participants, to be taught by the participants and learn about their experiences.

Data Collection

In preparation for the interviews, guides were developed which helped me to organise my thoughts and ideas about what the interview should cover, but also for confidence building prior to conducting the interview. I hoped that by preparing for the interview I would feel less apprehensive and more prepared when it came to conducting the interview, as opposed to worrying about what question to ask next. I also hoped that in adequately preparing for the interview I could be “present,” and focus on immersing myself in participants’ internal frames of reference. This was the intention, yet on reflection, this did not always translate into practice.

In the spirit of the reflexive nature of this research project, there were numerous opportunities for self-reflection and self-questioning during the data collection phase and subsequent data analysis phase of this study. Through this process of introspection, I believe I have changed and developed in many ways. Specifically, in terms of developing more knowledge and a better understanding, not only for topic under investigation as well as qualitative research, but also self-knowledge and awareness with regards to areas of weakness (e.g., conducting the interviews, performing the analysis, and challenges incurred in writing the thesis).

As the interviews commenced, it quickly became apparent that there were many complexities relating to conducting a qualitative research interview. I soon realised that conducting a research interview was substantially different to conducting a counselling interview. It became evident that a different set of skills and abilities were required. Yet similar “ways of being” are required, especially as an interviewer, operating in an existential-phenomenological study design requires similar qualities or “ways of being” that are required of an effective therapist, e.g., being mindful and present with research participant (Yalom, 2008).

According to Siegel (2010) “being a mindful therapist involves bringing an awakened mind to focus on things as they are with care and concern, literally [being] present in awareness with what is happening right now” (p. xv). Furthermore, an attitude of non-judgement, openness, flexibility, curiosity, and intentionality is also required. In my role as a psychologist, at times I find it challenging to be mindful and to stay present and fully engaged in what the client is saying rather than being in my head. At times I find myself disengaging with the client, and excessively thinking, analysing, or jumping ahead with somewhat bold interpretations about what could be going on for the client, and not fully attending to the clients and what is emerging. It takes patience and conviction to let go of

control and not drive an interview or push my own agenda, but rather allow the client to lead and to let whatever is going to emerge during the interview process emerge. I found at times during the interviews I was “doing too much” in the interview, especially at the initial interviews. I found that I was jumping in, asking too many questions, rushing the interviewee, and asking leading questions.

It takes courage to be open, unguarded, without agenda, to let go of control, and not to hide behind the role of an expert, in this instance a researcher or therapist, but rather hand over the reins to the interview, allowing them to be the expert. I recognise it is my role to tap into the interviewees’ resources, and give them the opportunity for personal growth through self-questioning, discovery, understanding and acceptance of themselves. Nonetheless I do not find this easy nor straight forward process. Moreover, it takes concerted effort to be aware and to bracket my own personal judgments, preconceptions and beliefs, and focus on the subject (client or research participant), like seeing them in their appearing for the first time, like a naive, curious child, in a wide open and flexible sense. I continuously work on improving my skills of developing a non-judgmental attitude. After listening back to the first interview I was aware of my need, desire, agenda to fit what the participant was presenting with the topic under investigation to suit and fit with the present study objectives. I was leading and did not appear unbiased. It was a prevalent learning experience and prompted substantial changes to my interview style. Hence the modifications to both the interview guide (most specifically the questions) as well as the interview style to be more non-directive.

I acknowledge that in this research project I am not a psychologist, that the interview was a research interview, as opposed to a counselling session. Nonetheless, I could not park my personality or what comes most naturally, personally and as a therapist, at the door. I was acutely aware of the many roles I was juggling. During this project I have assumed the role

of a qualitative researcher, a student, a conversationalist, a reporter, a recruiter, an ally, a presenter and as an interviewer.

During the interviews I found myself calling upon my training as a psychologist and applying micro-counselling skills, such as paraphrasing, reflection of feelings, and reflection of meaning. There were times when a participant expressed difficulty or became teary, it felt necessary (somewhat automatically) to validate his or her discomfort, and demonstrate empathy. However I cannot be certain to the extent that this may have influenced the interview, the relationship between me and the participants and ultimately the study findings.

Nonetheless, through demonstrating empathic understanding via the use of micro-counselling skills, it appeared to aid the process of double hermeneutics, that is, I was making sense of the participant making sense of their own experience (Smith et al., 2009), and reflecting back what they were saying. When I reflected back the participant, what he or she had said in their own words, or possible meaning or feelings; in some instances it appear to award the participant an opportunity to think more about their personal situation, which appeared to facilitate their processing and sense-making of their personal experience. And furthermore it simultaneously helped me to gain a better understanding and made sense of what the participant was expressing at any given time during the interview.

Each interview was unique, yet there were commonalities. Some I enjoyed, others not so much. I had an experience during early interviews when I asked, “are there any positives from your loved one being diagnosed with PD?” One participant said, “what an odd question”, and appeared quite offended. Whilst it is expected, it somewhat threw me, and made me tentative about asking the question at subsequent interviews. In fact, at some interviews I didn’t ask it, which is likely to have affected the study findings. If I had my time again I would change this. But I can’t and it is a limitation pertaining to data collection.

Some participants were eager to talk and share their experiences. Others were more closed and guarded. The majority of participants were willing to share their narrative, and required minimal prompting from me. This was evident in some transcripts where the researcher said very little, and the interviewee dominated the conversation. For some participants, they appeared to use the interview as an opportunity to talk and share their experiences. Evidence was provided by some stating that they enjoyed the interview, and that it had been “good to talk” and, “for someone to listen.” This may be considered a positive outcome of this project.

Data Collection Phase 2

In the research design phase, it was proposed that at the commencement of the focus group discussion the participants would be presented with a summary of the emerging themes from the individual interviews, and asked for their comments and views on these themes. However, there was concern at early interviews about the researcher leading at the interviews, and researcher biases in terms of the growth phenomenon, that is whether participants were experiencing growth or positive changes as a result of the PD caregiving experience, or whether they were being led by the researcher. To enhance reliability and validity of findings, it was decided to omit questions about growth and positive changes as a result of caregiving to see if participants organically reported positive changes without being asked or prompted at the focus group.

Moreover, I was concerned about the group being too small, although these participants generated a wealth of information. It was deemed that the group, albeit small, was sufficient to achieve study aims and objectives. Many things that the loved ones providing care reported during data collection phase 1 were also reported and further clarified and illuminated at the focus group. Although it was hard to tell whether this was a natural process, as a result of the more behavioural questions, or either all three attendees were

bouncing off each other, or possibility a combination of factors. Notwithstanding methodological limitations pertaining to the focus group are discussed in more detail later. Nonetheless it appeared that each participant engaged fully in the group discussion. I was less active in the focus group, and let the participants lead the discussion. I think was because I felt more confident with my interview style as a process of conducting the interviews and reflecting on my practice during the data collection process in stage one.

All attendees including the facilitator and note-taker shared jokes, and there were numerous intervals of laughter. The ambience appeared at times light-hearted, and at other times, during the group, the participants disclosed sensitive issues and information about their inner private subjective experiences.

Another notable aspect of the interview was that the participants identified with one another and had many shared experiences. Seemingly, the group benefitted from talking to each other. During the early stage of the group, at the 11th minute of the interview, Susan commented, “I feel these people [other participants] have been in my life.” This supports humanistic Rogerian theory that humans need to be validated, heard and understood.

The refreshment consisted of tea, coffee and a birthday cake because at the time of expressing an interest in participating in the focus group, one of the participants, Terry, had stated that it was his birthday on the date of the group. I made the decision to provide a cake to mark the occasion, which seemingly assisted in rapport building between attendees and may have contributed to the nice atmospheric tone for the remainder of the group. However, on reflection, I have concerns about whether this may have ultimately influenced study findings.

For example, an instance occurred which lead me to question whether the cake inadvertently influenced him in some way and led to demand characteristics. The concluding question on the interview schedule asked, “would you attend psychological counselling if it

was offered.” Terry responded by asking, “is it okay to say no?” His response may be precipitated because he was in the presence of two psychologists, and did not want to undermine the psychology professional. But his response could be better explained by feeling obliged to say “yes” to please the interviewer. It must be noted that Terry presented as somewhat of a positive impression manager; he appeared eager to please, and was very agreeable during the interview to both facilitator and other participants. It seemed that his behaviour might have been to avoid displeasing others or to avoid negative evaluation from others. This was evident in his self-report when he described performance anxiety associated with public speaking, although he challenged another participant, Noel, which provides evidence on the contrary to my speculations. It is very difficult to ascertain how and to what extent this influenced finding, but a notable factor nonetheless.

Data Analysis

Data analysis began during the data collection phase, and then during the process of transcribing the interviews, which to reiterate were transcribed verbatim. Phenomenological studies do not typically require as much detail in the transcripts as conversational analysis (Bazeley, 2013; Smith & Eatough, 2012). Nonetheless, oversimplified transcriptions have been criticised for losing meaning in the message conveyed, and ultimately understanding and interpretation of the message (Silverman, 2004).

Given this phenomenological study was concerned with ascertaining meaning and detailed descriptions of participants accounts’, it was paramount to retain accurate accounts of the participant’s original self-report and presentation (Gillham, 2005). Everything that the interviewee said, or what they didn’t say, was potentially relevant and important to informing this study. Charmaz (2001) and Frost (2011) advise that researchers pay attention to pauses, “you knows,” sighs, in-and-outbreaths, and “ums” as they appear to have difficulty expressing themselves; all of which can indicate a taken-for granted meaning or shared

knowledge assumption. Therefore, some conventions of conversational analysis conventions were used in an attempt to capture all verbal communication, nuances and utterances and possible implicit messages in the transcriptions. For example, recording the tone of voice, punctuation, pace, coughs, clearing of throat, utterances, shuttering, and non-verbal (e.g., coughs, sighs, nods, hesitations, observations of affect [e.g. anger, or crying, wiping tears away with a tissue, laughter]), to increase the likelihood of gaining fullest meaning.

Unfortunately, when checking the professional transcriptions it was evident (given the researcher had conducted the interviews) that the transcriptions provided by the professional transcribers were over-simplified, and relevant meaning had been lost. This could be attributed the professional transcriber not being provided with adequate training in the transcribing conventions aligned with chosen transcription methodology, prior to transcribing the interviews. I decided to add and ensure these conventions were consistent at the time of checking the professional transcriber's accuracy against the audio recording. However this was time-consuming. In future research projects, I would undoubtedly provide the professional transcriber with an extensive key, and adequate training, so that they were well versed in the transcription convention and methodology to promoting consistency, and reliability of analysis and interpretation. Moreover, it was essential that the transcriptions were accurate as they were subsequently coded by independent coders (described at phase 2: generating initial codes). This was advantageous because, through performing the aforementioned preliminary analytic tasks, it meant I, the researcher, was sufficiently familiar with the data before the "formal" analysis began.

Initially the data analysis stage was approached with enthusiasm. After conducting the interviews, transcribing the interviews and jotting down ideas, speculations and possible interpretation about what the data was "saying." I had a head full of ideas, and could not wait

to get the analysis done so I could write up the participants' stories about their PD experiences.

The development of portraits and the active reading stages was considered an exciting and creative stage of the analytic process. However, the practicalities of analysing qualitative data were more complex and involved than was initially expected. At the onset of the analysis I had anticipated that the coding process was a common sense, simple, mechanistic task. But I have since learned that coding is an art that needs to be practiced and polished to ensure proficiency.

My inherent sense-making, and meaning making mind, kept wanting to jump ahead to categorising extracts from the interviews into themes, or a nice, orderly fashion before adequately deriving the initial codes from the data (phase 2). I have since realised that this is a common misconception when working with qualitative data. I had taken what Bazeley (2013) said quite literally when likening this initial coding process to indexing in a book. Whereby an entry in an index (a code) provides a pointer to where something can be found in the text (Bazeley, 2013). I was coding with key words or categories rather than consistently retaining as much of what the participants said in the label of the code, to capture essence and meaning. Thus my early coding was more top-down than bottom-up, which resulted in substantial amounts of re-coding. Apparently this is common for novice qualitative researchers (Bazeley & Jackson, 2013; Finlay, 2011; Willig, 2012).

This is understandable, given people are meaning-making machines, with a bent for organising our world and experiences and world in to categories and schemas, based on existing knowledge. Hence, when I initially approached the data, my tendency was towards data reduction rather than data retention (Richards, 2009). After having the training and coding the entire data set, which ended up taking 6 months, I went to the other end of the

continuum, towards data retention, because I was overly cautious of going too far beyond the data in my interpretations, that is imposing my own preconceptions and biases on the data.

In retrospect, aligned with Smith and Eatough's assertions and speculations, the size of the present study sample was too large given the scope of a PhD project, and because the Student Researcher was the main investigator with the absence of a team of researchers to share the load. For the most part the Student Researcher conducted all the interviews, transcribed the majority of the interviews, and analysed all of the data. Consequently, at times, I did feel overwhelmed by the amount of data generated at the interviews and focus group. I did not want to end up producing a superficial qualitative analysis; rather I wanted to do justice to each case. Therefore, the analysis of the data took 7 months, (6 days per week), involved complete immersion in data, and included the development of portraits and mind maps. I was caught in the trap of (somewhat idealistically) not wanting to turn anyone away, especially considering the premise of the interviews, providing an opportunity to talk could have been cathartic, I did not want to deprive any willing participant the opportunity to reflect on the positive effects of caregiving, or tell their story, or to be heard and listened to. Therefore, for further research, a sample of six to eight would be preferable.

The conclusion of phase 2, which previously mentioned, resulted in over 1,500 codes. I found myself in a position whereby prolonged engagement (a few months) with the detailed and segmented task of coding, I felt so close to the data (transcript text), and consequently felt I had lost the holistic perspective of each case, and across cases that I had prior to commencing the initial coding. I was immersed in their story, their perspectives, by their accounts.

The portraits and mind-maps of participants were invaluable at this point. I was able to take a step back from the data and to regain a sense of each case holistically and in context (more top-down, but a useful way of bracketing). This helped me to regain a holistic

perspective before approaching the next phase, generating the themes, and once again adding my interpretation and calling upon a psychological mindset, grounded in existing theory to better make sense of the participants' accounts.

I maintain that had I not possessed a bent for understanding the dynamics of the individual, and performed the steps of the participants' mind-maps and portraits; the remainder of the analysis would have been superficial, and would not truly represent the complexities of each participant. Overall the hardest analytic tasks were to gain the balance between data retention and data reduction. I found it difficult to achieve a balance between generality and specificity in labelling the codes after coding a sample transcription, and before coding the entire data set (all 33 interviews). Given my limited experience in coding and working in NVivo, verification was sought from a professional Qualitative Data Analyst. The Analyst specialised in application of TA and IPA methodology in NVivo.

It quickly became apparent to the Analyst that the data had not been sufficiently coded. Unbeknownst to me, I had jumped ahead to stage 3 of the analysis. There were instances whereby categories had been created, categorised in a top-down fashion (deductive) rather than data driven (inductive) from the text. As a result, training was provided to enhance coding proficiency, and furthermore (and somewhat painstakingly) transcripts were re-coded to ensure code names sufficiently described text extract. For more details, refer to "reflections of practice – data analysis" at the end of this section. Once it was deemed that initial coding was adequate, only then could the study progress to the next stage.

Another challenge was to "not go beyond the data" (Braun & Clarke, 2006). In my role as a psychologist to assist an individual to gain a better understanding of themselves, that is, why they have come to be who they are and why they do what they do, I had to try and bracket my own interpretations or what was happening for them and how they had become,

and what I thought they were concealing or defending against. Staying true to the participant without imposing my own interpretations on the data.

As the interviewer during the data collection phase, I was constantly observing and interpreting, paying close attention to features and details of the participant's presentation (use of past or present tense, repetitions, incomplete sentences, metaphors, terminology, and so on). Possibly things that participant was either not aware of or took for granted. Obviously I was interpreting, making connections between parts and aspects of the data that the participant seemingly had not considered, and she or he may be aware of. There were times when I found myself doing this when I moved from the empathetic to more critical or speculative interpretation. It was not a linear process. Rather, I kept coming back to the transcripts or occasions, re-listened to the audio to stay grounded in participant's experience and what they had actually said. I was surprised how often I had misunderstood, or misinterpreted what the participants had said, and therefore it seemed that I had not bracketed my preconceptions, assumptions and speculations enough.

During the data collection and data analysis phase I made a concerted effort to disengage from literature pertaining to my topic area. There are varying viewpoints with regards to when a researcher in process of conducting research should regarding engage with the literature relevant to the analysis. Some argue that early reading can narrow the researcher's analytic field of vision, and result in focusing on certain aspects of the data at the expense of other potentially fundamental aspects (Braun & Clarke, 2006). Whereas Tuckett (2005) argues that engagement with the literature during the analysis phase stands to augment the analysis by alerting the researcher to more subtle features of the data.

Whatever workshop or conference I attended to keep abreast of evidence-based practices, attending workshops and conference, the PhD was always on my mind. After the data analysis, pre write stage I attended the World Parkinson's Conference in Montreal in

October 2013, it helped me to develop my knowledge of PD, and developed my understanding of the extent and magnitude of the non-motor symptoms associated with PD, and the absence of psychological support. This undoubtedly shaped the write-up of my thesis, especially the revisions of my literature. In fact, any learnings (or psychological theory) from workshops attended throughout the PhD were almost automatically related in some way back to helping me better understand the participants or for the presentation of my thesis. I maintain the attendance of workshops, most specifically the World Parkinson's congress enhanced my understanding of PD and ultimately improved the quality of the write-up of my thesis. The write up of this project like every other stage of this research project took much longer than expected. There were numerous times when I thought I would never finish. As I approach the 100,000-word count, an anecdotal quote comes to mind, "you think you can't, then it's done".

Appendix V: Previous theoretical model of Post-traumatic growth

Figure A3. Previous theoretical model of Post-traumatic growth

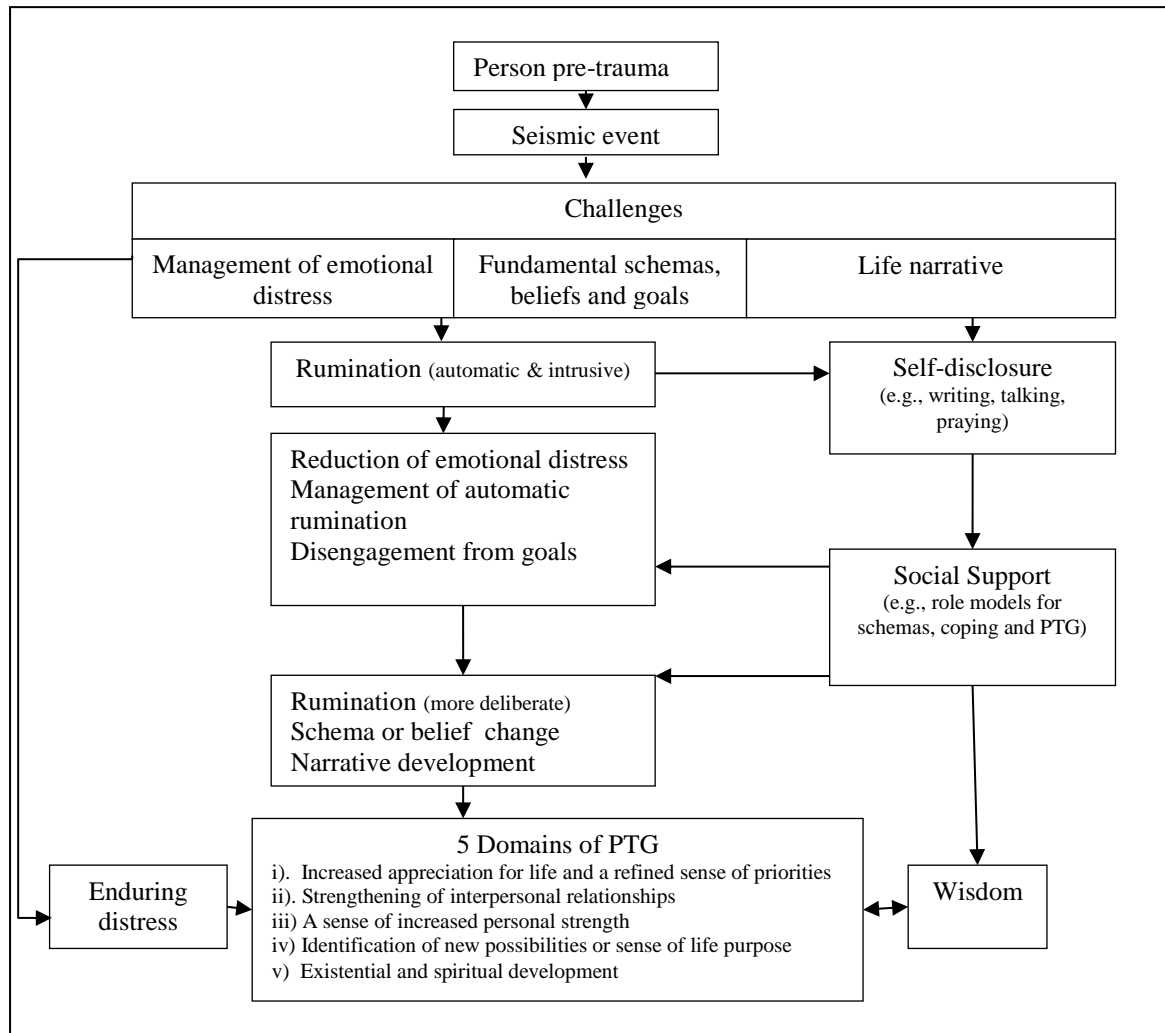


Figure A3. Post-traumatic growth model. Adapted from “Post-traumatic Growth: Conceptual Foundations and Empirical Evidence” by R. G. Tedeschi and L. G. Calhoun, *Psychological Inquiry*, 15, p.7. Figure A3 illustrates the previous theoretical model of PTG (Tedeschi & Calhoun, 2004). The model identifies five common positive psychological changes after adversity has been identified which include: (1) an increased appreciation of life and a refined sense of priorities; (2) strengthening of relationships; (3) a sense of increased personal strength; (4) identification of new possibilities or a sense of purpose for one’s life; and (5) spiritual development. As previously discussed in Chapter 7, the present study themes and sub-themes mimic the five domains of PTG.